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THE UNIVERSITY OF ALBERTA

RESOURCE USE IN THE HOME BY THE PATIENT WITH ADVANCED CANCER AND THE SPOUSE/CAREGIVER

by

NOLA WILLIAMS

(C)

A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND RESEARCH

IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE

OF MASTER OF NURSING

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EDMONTON, ALBERTA

FALL 1988

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(Signed) Nola Williams

8842 84 St

Edmonton, Alberta

Date: September 30, 1988

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FACULTY OF GRADUATE STUDIES AND RESEARCH

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled "Resource Use in the Home by the Patient With Advanced Cancer and the Spouse/Caregiver" submitted by Nola Williams in partial fulfilment of the requirements for the degree of Master of Nursing.

(Supervisor)

Date December 30, 1988

DEDICATION

This is dedicated with appreciation to the patients and spouses who participated, shared their experiences with me, and helped me learn so much. It is dedicated with love to my Uncle Art who also helped me learn so much.

ABSTRACT

The purpose of this descriptive study was to identify what resources the spouse/caregiver and the patient used to manage the care of a patient with advanced cancer in the home. In addition to identifying the type of resources used, the sources and usefulness of these resources were also described.

Interviews were conducted with a convenience sample of seven couples from a local cancer institute outpatient department. Subjects were patients between the ages of 45 and 66, who were identified as having advanced cancer, and their spouses. Three patients were attending a pain and symptom control clinic and four were attending the advanced gastrointestinal cancer clinic. Multiple methods were used to collect data. A focussed interview guide and an Family Inventory of Resources for Management instrument were used in data collection. Each individual was interviewed and each couple was interviewed once together. All interviews were tape-recorded and transcribed.

Types and sources of resources were identified through content analyses. The conceptual analysis indicated that both patients and spouses dealt with their major tasks of facing inevitable death or facing uncertain outcome by engaging in various types of "work". Work for the patients included hoping, daily living, preparing, maintaining, controlling, and fighting. Spouses work included hoping, helping, surviving, preserving, and

taking stock. The work of both patients and spouses was directed toward helping themselves and their families maintain a family life and combat the disease process.

One specific role of providing and interpreting information was identified for health care professionals. Patients and spouses wanted professionals to answer questions and provide facts in a way that was understandable and compassionate.

Results of this study provide direction for further research into the concept of work for patients and families in different stages of the life cycle and experiencing different disease stages. In addition, there is need for further investigation into communication patterns between patients, families, and health care professionals.

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CHAPTER I

STATEMENT OF THE PROBLEM

Introduction

The stressful nature of the experience for families when a member has advanced cancer has been well documented in both lay and health care literature. With very few exceptions, health care writers begin their discussion with the acknowledgment that cancer is the most feared of all diseases which carries with it a sense of impending death, stigma and isolation for the individual with the disease. It is within this context that families are expected to assume more care of their loved one with advanced cancer in the home for as long as possible and to the point of death, if that is feasible. This transition in the site of care from hospital to home for the patient with advanced cancer has implications for those health care professionals who provide and who will be providing support to the patients and their families. It is important, not only to deal with the traumatic effects of the disease, but also to identify the strengths and resources of the patient and family dealing with advanced cancer in the home. Information dealing with the resources used by patients and families is relevant to oncology nursing because it is often the nurses, in both the hospital and the community, who are directly involved in preparation of the patient and family for discharge

and in assessment of the subsequent care in the home.

Several studies have described problems experienced by both patients and caregivers when care is being provided at home. The most common problems for patients are pain, fatigue, sleeplessness, constipation, anorexia, and many other somatic symptoms (Cartwright, Hockey, and Anderson, 1973; Wellisch, Landsvert, Gurdera, Pasnau, and Fawzy, 1983; and Gotay, 1984). Agreement among researchers on what the problems are for the caregiver is not as evident. Some researchers report that the majority of families report good to excellent health (Pringle and Taylor, 1984); others report that family caregivers complain of headaches, sleeping difficulties, eating disturbances, and aches and pains (Welch, 1981). Giacquinta (1977) found in her review of 100 cancer families that isolation from the patient and role strain were problems for the family caregiver. Krant and Johnston (1978) reported communication difficulties between the family, patient and physician. Left largely unanswered is the question of what families do on their own behalf to manage the care of someone with advanced cancer in the home. Given the wide range of problems, physical and emotional, that patients and caregivers experience, it is important to examine what resources they use to cope with these problems.

Concurrent examination of both patient and spouse/caregivers has been done in relatively few studies, and then, only related

to specific concerns about what type of nursing interventions are desired (Freihofer and Felton, 1976). To overcome the perceived deficit in published studies, the focus of this present study was the marital dyad in which one member has advanced cancer. This focus was chosen because cancer brings stress to the whole family unit and to the marital subsystem in particular, as noted by Vachon, Freidman, Farmo, Rogers, Dyall and Freidman (1977). They reported that widows of cancer patients suffered more stress during the terminal phase than in widowhood and that they had more difficulties than did widows whose husbands had died of cardiovascular disease.

No studies of what patients and spouse/caregivers do on their own behalf have been reported in the literature. In light of the trend toward home care for people with advanced cancer it is important to identify the resources commonly used by patients and spouses in order that professionals may add to but not duplicate what patients and spouses have available. The identification of these resources will assist health care professionals to support and augment family resources but not duplicate existing ones. A clearer understanding of what patients and spouses do on their own behalf will provide valuable information that can be used to develop specific research tools or refine existing ones, which when administered to a larger sample size, would give generalized results.

Definition of Terms

For this study, the following definitions of major terms were used:

Advanced cancer - cancer for which it is no longer medically appropriate to treat the patient with the intent to cure the disease; rather, treatment is utilized only to control symptoms.

Resource - something to which one can turn in time of difficulty, a source of supply or support, a source of information or expertise (Webster, 1983).

Purpose

The overall purpose of this study was to answer the question: What resources do the spouse/caregiver and the patient use to manage the care of advanced cancer in the home?.

Research Objectives

Initially, the following objectives guided the study:

1) to identify the resources the spouse/caregiver and the patient used to manage care in the home;
2) to identify sources of these resources;
3) to describe the spouse/caregiver's and the patient's perceptions of the usefulness of these resources.

However, once the interviews were underway the information provided by patients and spouses replaced these objectives as a guide for this study.

CHAPTER II

REVIEW OF THE LITERATURE

Demographic Trends

The older age group within the population is increasing. Cancer is a disease which affects the older age group more frequently than younger age groups. In 1986, 80% of people with cancer were between the ages of 55 to 65+ (Canadian Cancer Statistics, 1988). Therefore, concern for home care for people with cancer will become even more important than it is at present and any improvement in identification of and effective use of resources will be vital.

Most statistics concerning people who receive care at home for advanced cancer come from evaluation studies or reports on hospice programs. Gotay (1984), for example, reported that in the second year of Calgary's Palliative Home Care Program involving 313 patients, 90% were between the ages of 45 to 65+ years, with the average being 62 years. Of the 313 patients, 134 were male and 179 female. The Edmonton program showed the same age and gender distribution (Zajac, 1985). The same age distribution was reported in a number of hospice evaluation studies (Parkes, 1978; Barzelai, 1981; Creek, 1982). Cancer was the diagnosis for 89% of the total home care cases in the Calgary program (Gotay, 1984), and for 87% of the cases in the Edmonton

program (Zajac, 1985).

Researchers have also reported that the spouse is often responsible for the majority of the home care. The spouse was the caregiver in over 50% of the 150 cases evaluated by Creek (1982). Zajac (1985), and Gotay (1984) also reported that the spouse was the primary caregiver in over 50% of the cases. Cartwright, Hockey and Anderson (1973) noted in their study of 643 people receiving home care that the most common sources of help to the patient were wives, husbands and daughters.

The older spouse caregivers may experience a decline in health and strength due to the demands of home care, therefore support to these caregivers is of concern to professional health care providers. The older adult is already facing major life changes such as retirement, loss of parents, and declining health. Financial resources may be fixed and social networks may be decreasing as a result of restricted social contacts, adding to the burden of care that these spouses must carry. Casseth and Hamilton (1979) and Gotay (1984) found that the obligation to provide care led to restricted social contacts for the family caregiver. Cartwright et al. (1973) found that when just the patient and spouse lived together, they were less likely to receive help from friends and neighbors than were those who lived with another family member or friends. Pringle and Taylor (1984), in their study of home care for 44 patients, found that

40% received care only from their spouses without help from anyone else. The questions of who helps these marital pairs, what help is best, and how to meet the needs of this older age group have yet to be answered. The older adults' home care experience with cancer has not been as well studied as younger age groups. The younger population's experience with home care for advanced cancer has been studied a number of times (Martinson, 1982; Martinson, Maldow, Armstrong, Henry, Nesbit, & Kersey, 1986); there is a need to look at support resources specific to the older age group.

Resources as Part of Coping and Social Support

The notion of resources is related to two concepts, coping and social support, which have shown promise as methods of studying how cancer patients and their families manage to deal with their disease. The study of coping has led to a broad view of the whole process of an individual's reaction to life situations. The study of social support has led to a narrower approach viewing a specific aspect of what helps an individual face a life event.

Resources as Part of Coping

Coping has been defined by Folkman and Lazarus (1980) as cognitive and behavioral efforts to handle external and internal

demands and conflicts. Haan (1982) stated that coping involves an attempt by individuals to overcome difficulties by reaching without, and within themselves, for resources to meet those difficulties. Whatever definition is used, resources play an important role in the coping process and may be a major contributor to the type of coping behavior chosen by individuals. The importance of resources for coping was noted by a number of writers (Pearlin and Schooler, 1978; Weisman, 1979; Moos and Billings, 1982). Stedeford (1981) found in his study of 41 couples facing death that the best copers had resources, although the study did not indicate what was meant by resources.

Folkman and Lazarus (1982) found in their study of 100 middle-aged people that the situation itself contributed more to the choice of coping behaviors than did any personality factor. They found that emotion-focused coping was more likely to be used when health was an issue and that problem-focused coping was more likely to be used if the problem was work related. If it is true that individuals do not approach problems in a fixed manner, then perhaps coping can be improved through enhancing or supporting existing resources. Since resources seem to be one of the key factors in successful coping, it would seem appropriate to isolate resources from the coping process and look at what resources are used, how they are obtained and what resources contribute to the management of advanced cancer care in the home.

Social Support as a Resource

Resources are also a central component in the concept of social support. Cobb (1976) defines social support as information which makes one feel loved, esteemed, worthy and part of a reference group. Information is certainly a resource, but Cobb's definition does not allow the inclusion of more tangible resources such as finances or physical assistance. Kahn and Antonucci (1980) use categories in their definition of social support which are of greater breadth. These categories are affirmation, affect and aids. However, these categories deal with the contributions of people in the individual's social setting and do not include what the individual utilizes as a personal resource.

Difficulties have been encountered when existing measures of social support have been used with the population dealing with cancer. Trewin-Nugent (1985) used Norbeck, Lindsay and Carrieri's (1981) social support instrument to measure the social support requirements expressed by family caregivers of terminal cancer patients. Trewin-Nugent found that caregivers could not relate to the love and respect questions intended to measure the affect portion of Kahn and Antonucci's (1980) model. In addition, the portion dealing with aids was not comprehensive enough to identify components of aid which were highly relevant

to this population. Several other problems in using existing instruments include: the extent of writing required to identify support networks may cause fatigue for this population; some instruments asked the subjects to project their need for support through identifying with a series of situation questions which are inappropriate for those experiencing a very specific situation themselves. Wortman (1984) indicated that many of the scales do not focus on problems prevalent among cancer patients nor do they allow for the identification of support from specific sources.

The various definitions of social support do not allow clear identification of the variety of resources which may be important to the patient and spouse/caregiver in a home care situation. In addition, the instruments developed to operationalize and measure social support have been based on these specific definitions and, as a result, measure only a portion of the possible resources. The study of social support has, however, contributed information about some of the resources which are of benefit to patients with cancer and their families.

Social Support Studies. The support of others can be a valuable resource for patients with cancer. It would appear that emotional support could be particularly important to this population. Mitchell and Glicksman's (1977) study of 50 patients

undergoing radiation therapy found that 86% of the patients regretted that they were not able to discuss the situation more fully with someone. Other researchers have also noted that communication can frequently be a problem for patients and family (Krant and Johnson, 1978; Reilly and Patten, 1981). Carey (1974) examined the effects of concern on the emotional adjustment of 84 terminal cancer patients and found that the best adjustment was among those who felt great concern from others with less favorable adjustment occurring among those who did not perceive concern from others. There are indications from retrospective hospice evaluation studies that support for families contributes to the success of home care and provides better adjustment for the surviving spouse during bereavement (Godkin, Krant and Poster, 1984; Cameron and Parkes, 1983). It is important to identify the resources, of which support may be only one, that will be of most benefit to the patients with advanced cancer and their caregivers before interventions can be planned or evaluated.

Specific Resources Identified from the Literature

A variety of studies carried out for reasons other than for the identification of resources suggest resources which may be important to people and families with cancer. Two studies identified that the family caregivers' biggest concern was for

the physical care of the dying patient, with items related to the caregivers' emotional support ranked as least important (Freidhofer and Felton, 1976; Skorapka and Bohnet, 1982). These studies, however, were conducted in hospital settings where nurses were the primary caregivers. When the spouses are the primary physical caregivers, they may have more need for emotional support than they did when someone else was responsible for the patient's physical care. These studies also forced the family caregiver to rank concerns. However, just because one concern takes precedence over another, it does not negate the overall importance of the other concerns. These studies did identify that the ability to provide physical care is an essential resource for spouse/caregivers; yet, Hine (1980) suggests that in our changing society, families have lost the skills required to care for an ill member at home. Grobe, Elstrup and Ahmann (1981) found that comfort care techniques employed by the family were never learned from a formal patient care provider. It is therefore necessary to discover what physical care the spouses provide, and how and from who they learn the caregiving techniques.

Even though the caregivers placed their emotional needs in a position of secondary importance (Freidhofer and Felton, 1976; Skorapka & Bohnet,1982), this does not mean that those needs can or should be ignored by health care providers. It may mean

instead that the studies were conducted in settings where the families may not have perceived their emotional care needs as a role to be met by the nurse. Rose (1976) found in her retrospective study of 26 family caregivers that the majority looked to the physician as a source of emotional support.

Information is one of the key ingredients for successful home care. Welsh's (1981) study of 41 family members of cancer patients found that one of their strongest needs was for information. Krant and Johnston (1978) reported that the type, amount, and manner in which the information was given had a major effect on how the family and patient communicated. In their descriptive study of 94 patients with late stage cancer and a variety of family members, Krant and Johnston found that the family members who were involved with and spoke with the physician initially, were more likely to continue to talk to the patient. However, if the family members were not spoken to by the physician initially or were angry about how they were told, they were then reluctant to talk to the patient. In addition, part of the difficulty with communication of disease information may have to do with the source of the information. In some situations, nurses are not viewed as an information source (Mitchell and Glicksman, 1977). It is important to examine the role that information, as a resource and its source, has on patient and family adjustment.

Conclusions from the Literature

Cancer affects the whole family, especially the marital subsystem since many of the spouses are the primary caregivers. Most cancer patients are in the older age group, and the older marital dyad make up the majority of the population dealing with the care of a member with advanced cancer in the home (Gotay, 1984; Zajac, 1985). The impact of cancer on the family system for an extended period of time may lead to the depletion of strength and resources in the older age group of caregivers. In addition, this group may have less access to help from outside the home (Cartwright, 1973). Stedeford (1981) found that the people with the most resources, not necessarily the fewest problems, coped the best. Therefore, a study of resources families use and which ones are the most helpful may be an effective way in which to plan assistance which allows families, as well as their friends and neighbors, to be active participants in the care of someone with advanced cancer in the home.

CHAPTER III

METHODOLOGY

Design

There is some information about the areas of social support considered important to caregivers and patients with cancer and about the coping of individuals with cancer. Also, writers have described the problems patients and the family caregivers experience during home care for an individual with cancer. Little, however, has been reported on what patients and their family caregivers do on their own behalf to manage the care of someone with advanced cancer at home. The purpose of this study was to discuss, from the individual's point of view, what resources the spouse/caregiver and the patient used to manage the care of someone with advanced cancer in the home. This study focussed on the types, sources and usefulness of resources utilized by spouses and patients in the home setting. A concurrent examination of spouse and patient resource use had not been reported in the literature and existing instruments, which would allow a quantitative approach, were not suitable. Therefore, a qualitative approach was deemed appropriate. Qualitative studies are used to categorize, classify, or conceptualize situations when the aim is to look at an old situation in a new way or to provide information in those

situations where no previous research has been conducted (Dier, 1979, p.100). For these reasons, this study utilized a descriptive, primarily qualitative, approach.

Data Collection

Multiple methods were used to collect data. A combination of qualitative methods including taped interviews, observations recorded in field notes, and diary notations were used. Quantitative data was also collected through the use of an instrument designed to obtain an inventory of family resources for management (FIRM) (see Appendix A). The potential benefits of this dual approach are that each method can build on the other and add different types of information (Cooke and Reichardt, 1979). Glaser and Strauss (1967) argue that the use of both methods can provide additional information and act as mutual verification for each other (p. 18).

An interview guide was developed based on the resources identified from the literature and suggested by subject experts (see Appendix B). The interview guide was tested for clarity and effectiveness with three couples who met the study criteria. Since no major changes were required in the guide, the information obtained from these couples was incorporated into the study.

The interviews were conducted in the couple's home, at times

convenient to them. The purpose of the initial interview with the couple was to explain the study and to collect demographic data. Subsequent interviews were conducted separately with the patient and the spouse. Each person was interviewed twice alone. The second interview was usually much shorter and was used to clarify any statements which were ambiguous from the first interview. The resource measurement instrument (FIRM) was completed separately by each husband and wife between the first and second interviews and was collected at the second visit. A portion of the final interview was with the couples to discover their shared feelings about the effect of the disease on their relationship, the effect of the interview, and to elicit from them any recommendations they may have for other couples facing the same situation and for health care professionals. The interviews ranged from 45 minutes to two hours in length. Each interview was audiotaped and transcribed to insure accurate representation of what each individual said.

Instrumentation

Data were collected using a focussed interview guide and FIRM. The focussed interview guide was developed based on resources identified from the literature. The guide was reviewed by three lay people who had or were experiencing home care for a loved one and by four nurses who worked in home care with cancer

patients and their families (two community based and two hospital based nurses). The reviewers were given a guide to assist them in the process (see Appendix C). As a result of these reviews, the interview guide was adjusted in wording and three questions which were deemed inappropriate were removed.

FIRM is made up of four scales which measure family strengths. These include: 1) esteem and communication, 2) mastery and health, 3) extended family social support, and 4) financial well-being. FIRM was developed for use in a population experiencing chronic illness (McCubbin and Patterson, 1981) but it has not been reported to have been used in a cancer population. The items, however, did not seem inappropriate for a family experiencing cancer. Only one change was made: question #25 was revised so that the word "social security" would read "Canada Pension". FIRM has a reported internal reliability of .89 Cronbach's Alpha (McCubbin and Patterson, 1981). Concurrent validity was determined when FIRM was compared to selected family scales such as cohesion, expressiveness and organization, and showed the expected positive correlation (McCubbin and Pattersen, 1981). As a research tool, FIRM has been used to assess family resources at any point in time (McCubbin and Comeau, 1987).

Sample

Subject selection criteria were as follows. Patients were

selected who: 1) were over the age of 45 years; 2) had their spouse as primary caregiver; 3) were able to read and write English; and, 4) were judged by the clinic staff to not be significantly burdened by participation in the study. For example, patients with severe fatigue, unmanaged pain, or unresolved psychological issues were not approached. In an attempt to limit professional input in how these couples were managing at home, they were not selected if they were on or had been on the city Palliative Home Care Program. The subject recruitment and interview phase of the study was carried out from April to August 1987.

A convenience sample of seven couples who met the criteria were selected, giving a total sample of fourteen individuals. The rationale for this number was that interrelationships are sometimes better understood with a detailed study of a few cases and, in fact, interrelationships may be missed with the use of a larger number of cases, especially when in-depth understanding is the goal (Agar, 1980, p. 123). To achieve in-depth understanding, questions must lead to a more exact understanding of the individual's point of view. This approach of increasing exactness and focussed questioning produces vast amounts of data for analysis, and large numbers of subjects would generate too much data for one researcher to manage with any degree of thoroughness. An additional rationale for small sample size is

the fact that this approach requires greater rapport and sensitivity between researcher and subject than is usually achievable or desirable in quantitative studies. Hinton (1971) suggests that in research dealing with a topic like dying, rapport is imperative. He indicates that it may not be a desirable trait for the investigator to remain strictly impartial and uninvolved with people who may already feel isolated and not able to talk about their feelings with families and friends.

The initial plan was to obtain subjects through the pain and symptom control clinic in a regional cancer institute. From that clinic, three couples were recruited immediately. However, one month then passed without any of the patients in this clinic meeting the criteria. It was decided to recruit subjects from another clinic within the institute. This second clinic looked after patients with advanced gastrointestinal cancer. Four couples were recruited from this clinic. Demographic data on each of the subjects is provided in Table I. All patients had metastatic cancer. Three patients had colon cancer, two had head and neck cancer, and one had liver cancer. Length of diagnosis was from 1983 to May 1987.

Data Analysis

Interviews were recorded, transcribed and subjected to qualitative analysis. Content analysis was carried out to

Table 1

Demographic Data

Couple	Age	Education	Years Married	Religion	Number of Children	Number of Household Members
Mr. A	55	UNIV	31	Prot	3	4
Mrs. A*	53	Post Sec		Prot		
Mr. B*	46	Sec	.5	Prot		
Mrs. B	44	Sec		Prot	1 (from previous marriage)	3
Mr. C*	54	Sec	25	Cath	2	3
Mrs. C	46	Sec		Cath		
Mr. D	68	UNIV	43	Prot	6	2
Mrs. D*	66	Post Sec		Prot		
Mr. E*	60	Post Sec	35	Prot	4	2
Mrs. E	62	Sec		Prot		
Mr. F	56	Sec	33	Prot	3	2
Mrs. F*	54	Post Sec		Prot		
Mr. G*	54	UNIV	17	Prot	2	3
Mrs. G	45	UNIV		Prot		

* = Patient

UNIV = University
Post Sec = Post secondary
Sec = Secondary

identify types and sources of support for the couples. In addition, the transcripts and field notes were read and reread to search out patterns, categories, and themes within the data that would explain what the couples were doing on their own behalf to manage advanced cancer at home. To ensure the validity of the conclusions drawn from the data, selected interviews were read by an expert in qualitative analysis and the categories and themes were examined. In addition, the themes and categories were reviewed with the final couple in order to validate that the representation was accurate.

Each individual was assigned a score on the Family Inventory of Resources for Management instrument (FIRM) to determine the resources each felt he/she had available for use. The total score was the sum of the four subscales which comprised the instrument. Small sample size and the method of sample selection prevented any generalizable information; however, FIRM results were compared to existing norms for the instrument. The FIRM results provided a quantitative validation of the qualitative data obtained through researcher observation and interview.

Ethical Considerations

Ethical approval was obtained according to the guidelines put forth by the University of Alberta Faculty of Nursing. In addition, ethical approval was obtained from the institution from

which the sample was obtained. In keeping with guidelines which protect potential subjects from coersion, individuals which met the study criteria were approached by the clinic staff and given a letter (see Appendix D) which explained the purpose of the study. If the potential subjects agreed, the researcher then spoke to the couples to further explain the study and to allow them the opportunity to ask any questions. If the subjects agreed to participate, they were then asked to read and sign a consent form. Each individual was assured of their right to: 1) refuse to participate, 2) refuse to answer any particular question, and 3) withdraw from the study at any time without concern for their future care. Anonymity was assured by not using any subject's name. Interviews were conducted in the subjects' home in a private location of their preference. Fatigue can be a factor for people with advanced cancer. Therefore, subjects were given opportunities throughout the interview to stop if they felt tired. None, however, wished to shorten the interviews. One interview was shortened at the researcher's discretion due to severe emotional reaction on the part of the subject. This interview was successfully completed at a later date. Although arrangements had been made to refer people in need to the nurse clinician with the pain and symptom control clinic at the regional cancer institute, none of the individuals required or requested this additional help.

CHAPTER IV

RESULTS

This chapter will present the results in four main sections: 1) resource types and sources, 2) resource meaning and identification of two patient groups, 3) fit between patient and spouse work, and, 4) responses of the couples when interviewed together. In the first section, the results of the content analysis of the resources according to type and source is presented. In the second section, patient characteristics, which lead to the identification of two patient groups are described. This section also includes a description of the meaning of the resources and how resources were used to accomplish a variety of work in which both patients and spouses were involved as they dealt with a diagnosis of advanced cancer. In the third portion of the chapter, patient and spouse resource use and work is compared. Finally, the responses of the couples when interviewed together are described.

Patient Resources: Type and Sources

Patient resources were divided into two types: internal and external. Internal resources were those strengths, traits or behaviors which originated from within the patients themselves and included things they did (activities) or mental processes

they utilized to manage their situation. External resources were further divided into two categories: physical and interpersonal. Sources of external resources were professionals, family and friends. A summary of the resources identified by the patients is provided in Table 2.

Internal Resources

Specific internal resources which the patients identified as part of their character were humor and mental and emotional strength. Faith was identified specifically by one patient as a source of strength. However, the role of religion, belief system and faith as support was unclear. These areas will be discussed in more detail in chapter five. Attitude played an important role for all of the patients:

> Mr. G.: A positive attitude can contribute to feeling better.
> Mrs. F.: I try to put my mind somewhere else... occupy my mind with something else.
> Mr. E.: Appreciate what you're doing and what you've got. It's a mental attitude ... I say to myself - get up and do it.

Some patients (4/7) viewed themselves as having the type of character required to face their situation. They perceived themselves as "outgoing", and "level, with no ups and downs".

Engaging in physical activities as a way of managing what was happening to them was important to all of the patients:

Table 2

Types and Sources of Patient Resources

Resources	Internal	External	
		Physical	Interpersonal
Types	Character	Medications	Positive attitude
	Faith	Information	Care
	Attitude	Psychological services	Comfort
	Self awareness	Help with daily living activities	Love
			Interest
Sources	Oneself	Professionals	Spouse
	Background	Spouses	Family
	Past experiences		Friends

Mrs. A.: Go out, run to the drugstore...go over to a friend's, read a book.
Mr. G.: It helps to change a lock or empty the dishwasher...you feel a little useful.
Mr. E.: Go to the shopping center, get my legs moving, don't just sit here.

The patients identified the source of internal resources as originating from within themselves. They perceived that these resources were due to their upbringing, childhood, background or past death related experiences:

Mr. B.: I come from a poor family and I was taught as a child you don't have something, don't envy someone else.
Mr. G.: I learned from my past experiences to deal with my feelings, not to fight emotions but to let them out.
Mr. C.: When you go to war and see people die just like mosquitos all over the damn place, for no reason, no thought ... then you know death exists...so it's acceptable. It's accepted that one day you're going to go.

External Resources

The majority of external resources were physical in nature, including either medications or information dealing with diagnosis, prognosis and treatment. Medications included analgesics, antiemetics, laxatives and sedatives as well as drugs for control of specific symptoms such as fluid retention and pruritus; professionals were the source of access to medications. Professionals were also the primary source of information though some patients (2/7) received information about vitamins or holistic medicine techniques from family or friends. Generally,

however, health care personnel were the providers of disease-related care and information about the disease, its prognosis and treatment. Patients wanted a professional available to answer questions and provide the facts in a way that was understandable and compassionate. Clinic staff were also viewed as the source for medications for controlling disease or treatment related symptoms, such as pain, nausea or constipation.

External resources in the form of interpersonal help included: care, comfort, love and interest. Care included such elements as providing physical help, preparing special foods and reminding to take medications. Comfort involved the provision of a nice environment, "encouragement when I'm down", and being listened to. One patient stated that she experienced love through her husband and family believing that there were things which could be done to help her and maintaining a positive atmosphere. To others, love was expressed through "hugs and what have you" and "someone to confide in, trust and talk to". It was important to patients that the family be interested in what was happening, and that they provide distraction for the patient through the family activities.

Interpersonal resources came primarily from families, in particular spouses. The majority of patients (5/7) named their spouse as their biggest source of help. Two listed their families generally; friends were important but families were

named first. The family's role was to listen, support, care, and provide expressions of love. Overall, however, the main source of help was from within patients themselves and was made up of perceived strengths, attitudes, and beliefs which gave them the determination to do their best in their situation.

Spouse Resources: Types and Sources

Spouses did not identify resources specific to themselves and their own need for care but only as they required help to care for the patient. The majority (5/7) directed their energies toward assisting the patient:

> Mrs. E.: I just have to try to keep up for him - think I can't get sick.
> Mr. F. I took active steps to reduce stress, made up my mind to do things with M (wife), and spend my time with her.
> Mrs. B.: Keep him comfortable - that's all I think of.

Types and sources of spouse resources were classified into internal and external types, as they were for patients. External resources were subdivided into two categories, physical and interpersonal. Sources of spouses' resources were themselves, professionals, family, and friends. An outline of the resources identified by the spouses is provided in Table 3.

Internal Resources

Spouses' internal resources were faith, attitude, and mental

Table 3

Types and Sources of Spouse Resources

Resources	Internal	External	
		Physical Help	Interpersonal Help
Types	Faith	Information	Talking
	Attitude	Psychological services	Relationship with patient
	Mental activities		Strength from children
	Physical activities		Support from friends
Sources	Oneself	Professionals	Patient
		Friends	Children
			Friends

and physical activities. Spouses did, however, discuss a great deal about the patient's character and about their life together. Faith or religious practices as a resource were cited more often by spouses than by patients:

> Mrs. E.: I pray to God to give me strength, that's the only strength I am going to get.
> Mr. D. I'm not a strong churchgoer, but I pray often.

Spouses, like patients, found a resource in their own attitudes:

> Mr. F.: Maintain positive mental attitude.
> Mrs. G.: Look at the positive, concentrate on strengths.
> Mrs. F.: I think things could be worse ... I have my health, I think of the future.

Controlling thoughts about the patient's illness was a mental activity for spouses in managing the situation. Thoughts could overwhelm them and interfere with their ability to provide the needed support to patients; therefore spouses used a variety of not only mental, but also physical activities to control their thoughts:

> Mrs. B.: I try not to think about it, I psych myself out, tell yourself you're not going to think about it and don't ... do something to keep your mind off it.
> Mrs. E.: I just try and block it out, work around the house, I feel better if I work.
> Mr. D.: Keep busy, doing things. I feel better if I'm busy.

Mr. F.: Don't let your thoughts run away with you, don't let sadness catch up with you.

Spouses, unlike patients, did not delve into their own character strengths nor did they elaborate as much on the sources of certain internal resources. They did not identify specific character traits or experiences as directly as patients did to explain the source of their inner resources. Yet, the major source came from within. Their statements were terse without elaboration or explanation for why they felt the way they did or what contributed to their internal resources:

Mr. F.: Do what you have to do and somehow or other you get the resources.
Mr. D.: I have endurance.

External Resources

Physical help from professionals came mainly in the form of disease-related information. In addition to information, one spouse utilized counselling services and two spouses were given medications by their family doctors to assist with sleep though they did not use the medications. Providing information was identified as the most important resource from professionals:

Mr. A.: What helped most was the specific information on treatments and side effects, with no false hopes, the truth ...the more you know the better.

Interpersonal help for the spouses centered mainly around communication. Talking to the patient, family or friends was a crucial resource to the spouses. Talking played a major role in the spouses' ability to withstand the pressures of the long term illness:

> Mr. A.: I need to talk to my close friend, I talk to my wife and the kids - talking it out is important.
> Mrs. E.: It helps to talk to my husband and children.

The relationship between patient and spouse provided another resource for the spouse. The patient's reaction to the situation however, had a bearing on how the spouse felt. The majority of spouses (4/7) indicated they actively and purposefully spent more time together with the patient in their day to day lives and also took more trips together. Two spouses admitted to having their time away from the home curtailed and that it was difficult for them to be at home more than usual. Four spouses named the patient as the person they most wanted to be with at this time; two spouses indicated that they most wished to be with their families, and one spouse listed friends:

> Mr. A.: I go to my wife even if she's sick I still go to her.
> Mr. D.: When she's depressed I have trouble getting her out of it, when she's down I'm down.
> Mrs. G.: He's my perfect companion.
> Mr. F.: I'm close to her, comfortable with her. I like to be with her and talk to her.

All seven couples had children, of whom four couples still had children living at home. In the situations where children were not at home, spouses reported that children provided interpersonal help in the form of being there when they needed to talk, being interested in what was happening and providing support in the form of letters and visits. In the other situations, where children were at home, spouses reported that children provided a sense of continuity, and the necessary elements of family life such as laughter, frustrations, concerns and joy:

> Mr. A.: I look at the kids and I know it is not finished.
> Mrs. G.: They provide joy, laughter, frustration and worry.

Friends were identified by spouses as being the major sources for support in the form of providing someone to talk to other than family for the purpose of distraction or advice about how to manage the situation. Friends were also a source of support by providing a social outlet:

> Mrs. C.: My friends listen to me and give me feedback.
> Mr. A.: I phoned P (friend) and asked him what I should do.
> Mrs. G.: Our good friends came over and gave us information on holistic medicine.

For spouses, as for patients, the major source of physical help was professionals. Sources of interpersonal help were the patient, their children, and friends.

In summary, both patients and spouses identified professionals as providing mainly physical resources in the form of information and medications. However, the majority of resources identified by patients existed as a result of their own inner strengths. For spouses, the majority of resources stemmed from family and friends.

FIRM Results

FIRM results were compared to existing norms for the instrument and, although not generalizable due to the small sample size, the results support the observations of the researcher and agree with the verbal report of participants. The couple which scored low on FIRM also reported a lack of family stengths in the area of communication and mastery of the situation, and were observed to display friction in their interactions by such things as raising their voices to each other. The couple with the least observable financial resources also scored lowest on FIRM's financial well being scale. FIRM scores are presented in Table 4.

Table 4

FIRM Scores

Couple	Esteem and Communication	Mastery and Health	Extended Family Support	Financial Well-Being	Total Score
Mr. A	38(H)	33(A)	6(L)	42(H)	119(A)
Mrs. A*	41(H)	43(A)	12(A)	47(H)	138(H)
Mr. B*	28(L)	45(A)	9(A)	15(L)	97(A)
Mrs. B	29(A)	38(A)	12(A)	20(A)	99(A)
Mr. C*	26(L)	17(L)	6(L)	40(H)	89(L)
Mrs. C	35(A)	28(L)	10(A)	41(H)	73(L)
Mr. D	Missing data				
Mrs. D*	36(H)	49(H)	10(A)	35(A)	100(A)
Mr. E*	35(H)	33(A)	10(A)	25(A)	103(A)
Mrs. E	38(H)	34(A)	12(A)	29(A)	113(A)
Mr. F	37(H)	32(A)	9(A)	40(H)	118(A)
Mrs. F*	36(H)	39(A)	8(A)	33(A)	116(A)
Mr. G*	37(H)	51(H)	8(A)	38(H)	134(H)
Mrs. G	44(H)	55(H)	9(A)	39(H)	147(H)

* = Patient

(L) = Low
(A) = Average
(H) = High

Resource Meaning

Reported in the following section are the results of the conceptual analysis of resource use by both patients and spouses. Addressed first is the delineation of patients into two groups according to the major task faced by members of each group. Task fulfillment required that patients engage in various types of work: hoping, daily living, preparing, maintaining, controlling and fighting. A description of each type of work is also presented. In addition, for each type of work, a discussion of the major goal and focus of the particular type of work will be included. Next, a description of the work of spouses is outlined. Although the spouses did not divide into two groups as the patients did according to any characteristic unique to them, they did face slightly different tasks depending on patient group. Spouse work included: hoping, helping, surviving, preserving, and taking stock.

Patient Groups

All patients had advanced cancer which had the potential of ending their lives in the near future. Within the total group, however, two groups of patients were identified according to their view of the inevitability of their death. Patients in each group shared similar characteristics which contributed to their perceiving death as inevitable or uncertain.

The first group consisted of three patients whose verbalizations about the fact that they were dying, indicated that they perceived their death as inevitable:

> Mrs. A.: This was the place I was going to die in.
> Mr. B.: Right from the beginning they (doctors) told me it was terminal.
> Mr. C.: You have to accept that you have to die sooner, you have to die sooner than you wanted to.

Common characteristics of these patients were that: 1) they had been told by their physician that their disease was terminal; 2) they no longer were receiving any anticancer treatment; 3) they did not feel anything would help now; and 4) they had physical symptoms requiring interventions. They displayed symptoms of pain, weight loss and decreasing mobility. The major task for these patients was facing the inevitability of their death.

The second group of four patients, although realizing the potential for death existed, did not feel that death was an immediate threat:

> Mr. E.: They (doctors) tell you right out ... they say "that's it buddy". ... I think about things that will be when I get better. It's the only assumption I can make.
> Mrs. D.: I don't think about it too much. I don't, I just go from day to day and don't think I have cancer.
> Mrs. F.: I think the very important thing is not to give up. I'm sure there are people that die every day that haven't given up but whether they die or not their life will have been different and they won't have suffered as

much in the time that they lived through it.

In contrast to patients in the first group, the characteristics of these patients were: 1) they were either still receiving anticancer treatment for control of tumor growth or had a desire for further treatments; 2) they were either not experiencing physical symptoms or had symptoms but denied the need for intervention; and, 3) with the exception of one patient, their day to day lives were not physically impeded by the cancer diagnosis. Generally, they were not experiencing the problems of pain, weight loss, and decreased mobility to the same degree as the first group. The major task for these patients was dealing with the uncertainty of disease trajectory and outcome. A summary of the characteristics of the two patient groups is provided in Figure 1.

Patient Work

For all patients, work was an important issue. Work was required in order to deal with each of the two major tasks of either facing the inevitability of death or dealing with an uncertain outcome. Regardless of the task, the types of work and the goal of each type were similar for all of the patients. However, the specific focus of each type of work, as evidenced by the things they did, and resources they used, differed depending on whether the patient was facing inevitability or uncertainty.

Figure 1

Patient Groups

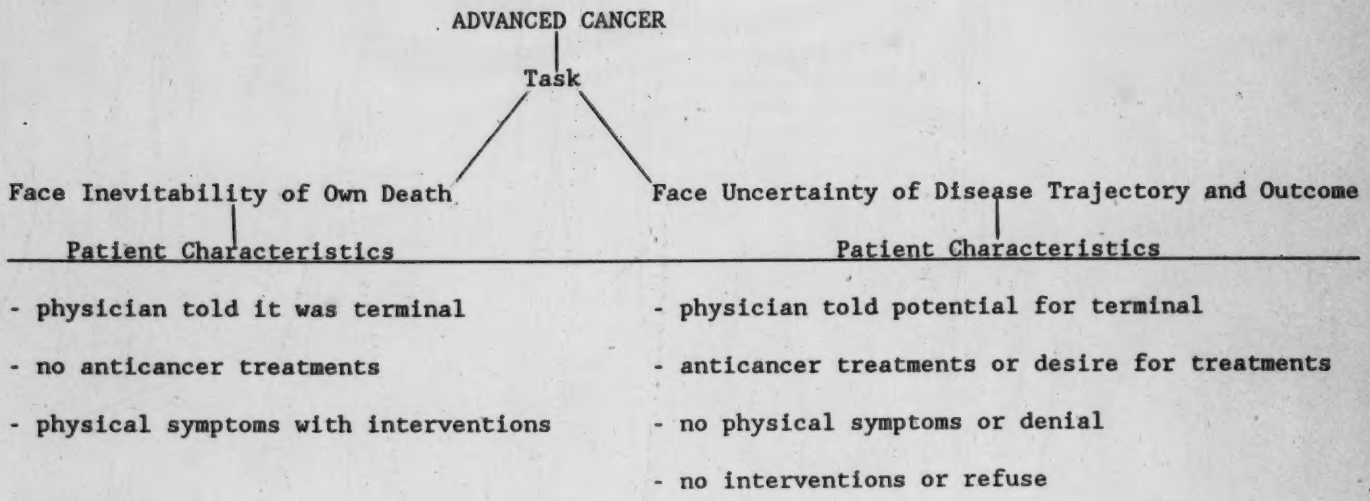
ADVANCED CANCER
Task
Face Inevitability of Own Death
Face Uncertainty of Disease Trajectory and Outcome
Patient Characteristics
- physician told it was terminal
- no anticancer treatments
- physical symptoms with interventions
Patient Characteristics
- physician told potential for terminal
- anticancer treatments or desire for treatments
- no physical symptoms or denial
- no interventions or refuse

Table 5 gives an overview of the types of work which enabled patients to manage their respective tasks.

Hoping Work

The goal of hoping work was for an optimal/desirable outcome. The focus of the work changed from being disease-oriented in the uncertain group to comfort-oriented in the inevitable group. The work of hoping for the uncertain group had an element of "not giving up on things we can do".

An important resource which nurtured hope, particularly in the uncertain group, was the attitude of spouses, families, and friends. The attitudes which were helpful communicated "never giving up", "positive thinking", and "not shying away". The availability of medical treatment for the disease also fostered hope. One patient in the uncertain group, when told an investigational drug would not be available, went on to say "I don't think there is much hope". In comparison, another patient in the same group was more fortunate and gave this response: "Well, we got good news from the hospital that the treatment is working, so that helps". Subjective and physical signs of improvement or lack of physical limitations also supported hoping work:

Table 5

Patient Work

Type of Work	Goal	Focus	
		Uncertain	Inevitable
1. Hoping	To achieve an optimal/ desirable outcome.	Seeking disease-related outcomes.	Seeking comfort related outcomes.
2. Daily Living	To go on living a meaningful life in spite of cancer.	Outlining generalities of normal life.	Outlining specifics of how they manage.
3. Preparing	To plan ahead in order to equip the family to manage following the patient's death.	Worrying and thinking about the future.	Carrying out explicit and concrete actions for the future.
4. Maintaining	To maintain the support from others and to help others deal with the situation.	Recognizing the importance of their attitudes on the family's support and ability to manage.	Recognizing the importance of their attitudes on the family's support and ability to manage.
5. Controlling	To control self in the situation.	Utilizing physical and mental processes to manage thoughts: use of mind to heal body.	Utilizing physical and mental processes to manage thoughts: recognition of limitations and concern for energy conservation.

Table 5 (cont)

Patient Work

Type of Work	Goal	Focus	
		Uncertain	Inevitable
6. Fighting	To do the best they could against the disease.	Looking ahead to a war. Preparing to engage in a fight.	Engaging in specific battles, meeting specific goals; they acknowledge they will lose but that they will still fight.

Mrs. F.: Well, the fact that I feel stronger and I'm feeling better, I've gained weight, helps me hope.
Mrs. D.: I pretty well have carried on the way I always have. I don't think there is too much change.

Hope was for a cure and the patients did not see time as a critical limitation for their hope:

Mrs. F.: My husband says I can just hang on until they find a cure.
Mr. E.: I hope that I get cured. That's my main hope for now.

The elements of time and optimal outcome are further revealed by one patient in the uncertain group when she elaborated on her hoping work:

Mrs. F.: Hope is not necessarily meaning that I hope for another forty years of life. It means quality of life to me. Hope that I can be mobile ... hope that there will be more learned about cancer. It's not just one hope, it's many.

For the inevitable group, time was a limiting factor. These patients focussed their hope within shortened time expectations; hope was for "a good day". The focus of hope work changed over time as patients became more ill, as evidenced by one patient in the inevitable group:

Mrs. A.: I have had cancer for almost two years and of

> course the first time ... you're sure that chemo is going to work. ... I am not living the type of life that I would choose but I am still living and feeling fine. I hope that continues.

Patients in the inevitable group struggled with the dilemma of wanting to live and also wanting the suffering and dependency to be over. One patient in the uncertain group shared these feelings when his pain forced him to question his desire to push himself in order to get better:

> Mr. E.: If I've had a real terrific bowel attack ... a lot of pain ... I say to myself, "What's the sense of life. It's not worth it."

Generally, the time frame in which hope was viewed changed from unlimited in the uncertain group to weeks and days in the inevitable group. In addition, the focus of hope changed from cure or control of the disease in the uncertain group to comfort for today in the inevitable group.

Daily Living Work

The goal of daily living work was to go on living a meaningful life in spite of having cancer. The focus was on maintaining as normal a life as possible. The activities described by the patients reflected a narrowing down from generalities in the uncertain group to specifics in the inevitable group. This trend was evident in their descriptions

of activities and in their relationships with others.

Resources which contributed to their daily living work were mainly the patients' own physical activities, attitudes, and their deepening sense of self awareness. For the uncertain group priority setting was important, "I do more of what I like". Patients in the inevitable group developed a deepening sense of appreciation for doing the simple activities of living such as "picking up around the house".

Patients in the uncertain group spoke in more general terms about the things they did in order to achieve the goal of going on with life in spite of cancer:

> Mr. G.: Try and sort of carry on and do things as we would normally do things and face things as they appear.
> Mrs. F.: There's a feeling of live for today and let the future take care of itself....

In contrast, inevitable group patients were much more explicit in describing things they did:

> Mrs. A.: I cleaned the fridge on Saturday. You'd think I cleaned the whole house, I felt so proud of myself ... getting on with something using my hands is really a boost.
> Mr. C.: I was able to walk around without my cane nice and slowly and do things, and empty the dishwasher, pick up a few things here and there and make myself a little bit useful.

Relationships with others were a part of the work of daily living. The same narrowing from general to specific descriptions

was evident when the two groups of patients were compared. In the uncertain group, statements were general:

> Mr. G.: Friends are treating me in a sort of natural way and I kind of like that.

Interactions, as reported in the inevitable group, were more specific:

> Mrs. A.: I always feel better if somebody would argue with me for a little while.
> Mr. C.: Here they (friends) came. Boy we drank so much wine it wasn't even funny ... We didn't get drunk but we had fun.

Finally, uncertain patients spoke about evaluating who they spend their time with and how they would carry on now that they have been diagnosed with cancer:

> Mrs. D.: Maybe it's made me do a lot more, or maybe I make more effort to associate with people I like more.
> Mrs. F.: I probably keep in touch with people more ... getting out and doing some play exercise rather than boring house work.

Patients in the inevitable group did not offer such descriptions of priority changing. It was not relevant to them at this point.

Preparing Work

The goal of preparing work was to plan ahead in order to

equip the family to manage practically and emotionally following the patient's death. Information was the principle resource which allowed the patients to engage in preparing work. Preparing work involved two aspects for patients: getting information from professionals and giving information to their families. Getting information was much more vital to the inevitable group than to the uncertain group.

Comments from the uncertain group reflected that they were satisfied with the information they were given; they were less aggressive about getting the information:

> Mrs. F.: The doctor told truthfully everything he knew and what we could expect.
> Mr. G.: I found Dr. Y very patient and very meticulous in describing things to me.

Once these patients had the information, they described a sense of worry and thinking about what to do in a general way:

> Mrs. F.: ... we all went to Hawaii last Christmas and I guess we thought that it would be our last one together so all the children went.
> Mrs. D.: ... maybe in the back of my mind paying more attention to what I'm going to do with everything in the house and that sort of thing ...
> Mr. G.: ... that upset me the most, realizing that there was going to be an end to the relationship, our family relationship.

In contrast, patients in the inevitable group displayed a sense of urgency; they demanded information, asked for the truth,

and were angry at any possibility that the truth may be withheld from them:

> Mr. C.: (You are told) everything's gonna be all right. He (doctor) knows already that the goddamn thing went down through the lymphs to my chest, but I wasn't told.
> Mrs. A.: But the hospital does not give you any information unless you ask for it. They don't volunteer the information and I guess that's the principle they work on. If you ask questions, you'll get the answers, if you don't ask there is going to be nothing volunteered.

Furthermore, these patients described more explicit and concrete actions. Once they had the information, they set out to help their families manage the details of their own lives after the patient died:

> Mrs. A.: I am doing a list of things in the house that get a yearly cleaning and how to take down the sheers. I finished a book of recipes. I have been given time, not like people who have a heart attack or a car accident you know, their house is in a turmoil.
> Mr. C.: I have been able to linger around and tie up loose ends instead of just leaving them in chaos. I bought the kids things that I wanted.

As a way of preparing the family, and also as a way of preparing themselves, the uncertain group talked. Talking helped them come to a realization that a dramatic change had occurred in their lives, but, they talked only to a certain degree and about general topics:

Mrs. F.: I've told my husband, you know, in some ways how I feel but - and, of course, you can talk about the treatment and the aspects of it in that respect but you just can't go on talking about your emotions all the time because it doesn't help you sort things out.
Mr. G.: Well, I confided mostly in L (wife). I think I must have had some resistance to accepting it because I remember being annoyed and angry when ... other people were told about this.
Mr. E.: We talk about it pretty well when I want to talk about it.

Patients in the inevitable group reflected less need to talk. Instead, these patients were more active in preparing themselves for specific events:

Mr. C.: ... the other day I called the priest and said "is it okay if I have, if I have myself cremated first and the services after?"
Mrs. A.: I went to the hospital to look at the palliative care unit ... I thought if I can first see it while I'm healthy, (it will be better) than when I'm sick and then wonder what to do.

In preparing work, the focus of the uncertain group was on general thinking and worrying about the future within an ambiguous situation. In contrast, patients in the inevitable group described concrete behaviors and well-thought out strategies as they prepared their families and themselves for death.

Maintaining Work

Of the six types of work, maintaining work is the only type

where the focus of the patients is the same for both groups. As well, the principle resource for both groups was the patient's positive attitude. The goal of maintaining work was to maintain the support received by the patients from others. There was an awareness amongst the majority of the patients (6/7) that their attitude toward or reaction to the situation had an impact on others, and that these attitudes and reactions could ease or worsen the situation for family and friends. They were also aware that their attitudes and reactions could strengthen or weaken the support they received from family and friends. This sense of impact on others was reflected in the following statements:

> Mrs. A.: To go around weeping and wailing all the time though, that's not good, because what can my family do?
> Mr. C.: Well, I'm trying to let them (family) see that I'm serene about it .... that I'm content.
> Mrs. F.: Try not to inflict your despair or whatever on the rest of the people around you.
> Mr. G.: I think that they (family) kind of look out of the corner of their eyes and say "well I don't see anything different" ... I have an attitude that I'll accept things as they are now and feel alright and we'll just carry on and they can see that and I think that helps them too.

Maintaining work also had to do with the patients attempting to maintain regular family life for the sake of their families. This was best reflected by the following statement:

> Mrs. A.: I won't allow the cancer to eat away at the very

fabric of the home because when you're young, you can't take that.

Ensuring continued support and conserving the energies of family and friends was also maintaining work:

> Mrs. F.: The more you're positive, the more help you get from other people, and the easier it is for them to be around you.
> Mrs. D.: I wouldn't want to burden friends with problems.
> Mrs. A.: I think I use my husband to lean on, sometimes too much, because as I say I think I see a nervousness in him. I'm going to have to learn to use him and not to abuse him.
> Mrs. A.: I know my friends that come over, they'll say "how are you?" and I'll tell them briefly and then we are on to something else because they would get tired of me, you know, it would become a chore for them to visit me.

Patients in both the uncertain and inevitable groups described maintaining work. However, as with the previous types of work, patients in the inevitable group were more specific than those in the uncertain group about how they accomplished maintaining work:

> Mrs. A. (inevitable group member): He (husband) was invited to a hockey game. I couldn't go, but I insisted he go and I think he was better for going. His problems are just as serious as mine you know because I have cancer, but he has me.

Controlling Work

The goal of controlling work was to control the various

aspects of self in response to the strain of having a cancer diagnosis. The resources of importance here included a variety of mental processes and physical activities. One technique common to both groups had to do with keeping control of thoughts through keeping physically busy:

> Mrs. A.: Your mind goes in circles being alone, so sometimes it is just go to the drug store, talk to someone or go to the bank.
> Mrs. F.: Occupy your mind with something else ... physical exercise, or reading, or talking to somebody about something entirely different, to get your mind occupied in another area.

Approaches to controlling the physical self differed between the two groups. Patients in the uncertain group worked at regaining control of their physical bodies in order to work toward being healthier:

> Mr. G.: I remember, before the operation, doing some relaxation exercises to try and relax my body as much as possible so that I could cooperate as much as possible and contribute what I could towards the effort to try and do something about this.
> Mrs. F.: I felt if I was relaxed, I could accept the treatments better.
> Mr. E.: If I feel myself getting tense I just go through my relaxation tape, lay down and make myself relax.

Patients in the inevitable group however recognized that there were limits to how much control they could have over their bodies, and instead, focussed on careful management of their time

and energies in relation to the environment:

> Mrs. A.: I like to go to someone else's house - because I can control the visit, I can leave when I get tired.
> Mr. B.: I don't want to strain myself. I don't want to put myself under any stress. I realize I am not strong enough.
> Mr. C.: I was trying to cut down (on pain pills) to show I was in control. Now I realize that the pill is there and I haven't got that much control, so I take a pill in order to help myself.

Acknowledging lack of control over their bodies may have stemmed from an increased awareness of their total "self" in the situation. These patients in the inevitable group were more likely to sense the presence of their inner resources and had a more integrated view of themselves:

> Mrs. A.: Sometimes you cannot wait for outside intervention. You have to do it yourself and it helps.
> Mr. C.: ... there's more inside me trying to come out and it's trying to come out with the help and the understanding of others.

Patients in the uncertain group, in contrast, displayed less integration of body and mind, and their comments showed a separation of themselves from the situation:

> Mrs. D.: I don't think about it (cancer) too much. I just go from day to day and don't think that I have cancer. I have always tried and I think successfully to sort of compartmentalize my life ...
> Mr. G.: I sort of try to step out of my situation and look at it.

The patients used a variety of ways to attempt control of "self" in order to either help their bodies to heal or conserve their energies. The inevitable group displayed more energy conservation tactics and used statements which showed a realization of the limits the illness placed on them, leading to more integration of body, mind and emotions than was evident in the uncertain group. The uncertain group was more likely to force themselves to participate in activities as normal or near normal as possible in spite of the disease. This approach was evident even with one patient in the uncertain group who had physical symptoms:

Mr. E.: I push myself ... even when I'm tired.

In contrast, a patient in the inevitable group responded to his limitations in the following way:

Mr. B.: I realize I can't do it (go on a day trip).

Fighting Work

The goal of fighting work was for patients to do the best they could against their disease. Resources included their own character strengths, attitudes, and desires to attain certain goals. In addition, support in the form of a positive outlook by

family and friends was important. Both groups discussed "fighting" the situation. Patients in the uncertain group frequently used the term "fight it". They identified things which helped them fight but again were less specific than the patients in the inevitable group about what they were fighting. Two patients in the uncertain group said:

> Mrs. F.: Just the support of the family and friends was really the big thing that made me able to carry on and to try and fight this situation.
> Mr. E.: As long as I got my two feet and my head's still working, I guess we're still fighting.

Mr. C. was a member of the inevitable group; he was specific about what he was fighting:

> Mr. C.: Battling an illness and battling cancer is fine and dandy - you have to. You can't let yourself down without a fight, you know, and even when you realize that you're on the losing end, you still have to battle. You don't want to be caught dueling there, and just because of a moment's disattention, you get your head cut off. You continue the duel and say "Hey, if you want to get me, Buddy (death), you'll have to get me, but I'm gonna make you sweat for it".

Similarly, another member of the inevitable group discussed in specific terms the goals he had to fight for:

> Mr. B.: ... he (doctor) said "Don't make any long range plans". He said, "You could have a few days, a few weeks". In my own mind, I said, "To hell with you. I'm going to live until I can't stand no more." By all rights, he told

> me I'd be dead six months ago. I'm still here and I plan to be here in August ... to visit my mother's grave, then there's our anniversary in October, then Christmas. There'll be one goal I won't make, but it will be the last one.

Patients in both groups referred to their fight as fighting in a war. One major difference, however, existed between the descriptions of the two groups. Members of the uncertain group appeared to view themselves as in a war or as getting ready for war; whereas, the descriptions of the inevitable group members indicated that they had been in a war, and although they had lost some of the battles, they decided to continue to fight, aware that they cannot win the war. Only three patients did not refer specifically to "fighting"; of these, one preferred "not to think about it", the second "accepted the situation", and the third was "determined never to be angry". It seems, therefore, that in order to fight, patients needed to acknowledge, but not accept, the threat, so they could mobilize their forces (anger) against it.

Even as their war was ending, patients in the inevitable group maintained their fight by comparing themselves to others - to those whose battle scars were worse than their own. Seeing others worse off than they were seemed to encourage the patients in their fight:

Mrs. A.: I think I am extremely lucky compared to people

who are widowed or who are alone.
Mr. B.: I look at people in wheelchairs and at least I'm getting around.
Mr. C.: When somebody tells you that you are going to die ... and you're going to have time to do things and solve some problems ... it's much better than no notice whatsoever like being killed on the street or in a plane crash.

Members of the uncertain group did not compare themselves to others. Perhaps these patients were more aware of the health of others and were inspired to strive for health; patients in the inevitable group looked at people who the war had left in worse condition as their source of inspiration. Whatever the reason, seeing others whose functioning was more limited, or hearing of deaths where the deceased had not had time to prepare their families, appeared to give the patients in the inevitable group encouragement.

Summary

Patient respondents in this study faced one of two tasks: dealing with the inevitability or dealing with the uncertainty of their own death. Those who were facing the inevitability of their own death were no longer receiving treatment, had been told by their physician that their disease was terminal, and had physical symptoms which required intervention. Those facing uncertainty were still receiving some form of treatment or had a desire for more treatment, had been told by their physicians of the potential for a terminal result, and were not experiencing

physical symptoms, or had symptoms but denied the need for interventions.

Patients in both groups engaged in various types of work in order to manage the major task. Six types of work were delineated, and for each type, the goal of the work was described. The focus of the work in meeting the goal differed for the patients in the two groups. Generally, the inevitable group members described their actions with much greater specificity and detail. For example, patients' descriptions in the inevitable group included: "clean the house", "change a lock", "laughing and joking with friends", and "getting out for a drive". Within the uncertain group, descriptions were general: "carry on normally", and "doing what I like to do". Their language also reflected this narrowing specific perspective; for example, the pronoun most used by the inevitable group was "I". The pronouns used by the uncertain group members, however, were more often third person, such as "we're", "our", and "everyone".

The inevitable group talked about the situation in definitive statements, such as "I accept it", compared to statements from the uncertain group of "sort of face it", "sort of live with it", and "live with it, I guess". Although one patient (1/4) from the uncertain group spoke of accepting it and mentioned that he made sure his life was in order, the comments of individuals in the uncertain group generally did not reflect

the same attention to detail as did those of the patients in the inevitable group.

Spouse Work

Spouses, as did patients, had a major task to face. Their task was to deal with varying degrees of uncertainty concerning the outcome of the patients' illness. For the spouses of patients in the uncertain group, the task was to acknowledge the seriousness of the situation and the possibility of an earlier than expected death occurring within an unknown time period. The spouses of patients in the inevitable group had to acknowledge the possibility of death occurring within a shortened time period. These tasks were more similar, from the point of view of degree of uncertainty attached to them, to the tasks faced by the patients in the uncertain group than they were to the tasks faced by the patients in the inevitable group.

In order to acknowledge the possibility of death, spouses, as did patients, engaged in a variety of work. The spouses' work was similar regardless of the task they faced. Few similarities between the spouses' and the patients' work existed. The major difference between spouses' and patients' work had to do with the focus of the work. Patients' work focussed mainly on themselves, and their descriptions became more specific and detailed as they were able to appreciate the imminence of their death. Spouses'

work focussed mainly on the patient, and their descriptions were generally more diffuse than specific. All spouses, within the boundaries of their strengths and weaknesses, worked at doing their best for the patient. They applied their energies to the task of caring for their ill husband or wife for an undetermined length of time, facing an outcome that had a varying degree of uncertainty attached to it. Mr. D., whose wife was a member of the uncertain group, described what he was to face: "It's going to be bad, I know that it's going to be bad".

Spouses had the difficult task of facing an uncertain future and the possibility of the loss of their loved ones, while at the same time, living for the present now and trying to contribute to the patient's well being while he/she was alive:

> Mr. F.: .. we just did everything that was necessary to make things easier for her, so that we could spend as much time with her and help her to feel as if there were some people that cared about her, so she'd care about herself.
> Mrs. G.: It wasn't until K (husband) said "You're treating me as though I'm already dead", that I suddenly turned things around and began to look at the positive side of life and we're on a very even plane, I think, now.

Spouses' responses were categorized into five types of work. An overview of their work is presented in Table 6.

Hoping Work

The only type of work that was common to both patients and

Table 6

Spouse Work

Type	Goal	Focus by Patient Group	
		Uncertain	Inevitable
Hoping	To have a desirable outcome for the patient.	On global hopes for cure or a miracle.	On specific hopes for patient comfort, short term goal attainment and spiritual re-unity.
Helping	To protect and care for the patient and family.	On giving mainly psychological support, being positive.	On giving physical as well as psychological support, maintaining a role for the patient.
Surviving	To "hang on" or "carry on" during the situation.	On managing the strain of uncertainty in disease outcome in their loved one's illness.	On managing the strain of watching their loved one's progressive illness.
Preserving	To keep the family and its memories intact.	On creating memories, concentrating on enjoying family life and the patient, changing priorities.	On reviewing memories and healing the hurts of the past, making the most of the time left.
Taking Stock	To assess the pre-illness life with the patient.	On reviewing the patient's character and their shared experiences.	On reviewing the patient's character and their shared experiences.

spouses was hoping work. For patients, the goal of hoping work was for a desirable outcome in relation to the disease or to comfort, but the goal for spouses' hoping work was for a desirable outcome for the patient. The focus of the spouses' hoping work changed according to which patient group their husband or wife belonged. Hope figured more prominently in the spouses of patients in the uncertain group; these spouses' hopes were more global in nature:

> Mr. D.: I'm hoping they will find a cure for cancer.
> Mr. F.: The so called miracle cures come from somewhere - so why can't I have one here.
> Mrs. E.: I just got it in my head that I keep thinking there's going to be a miracle, he'll be cured ...

For the spouses of patients in the inevitable group, hope was for physical comfort, was limited in the sense of time, and in one case, was for spiritual hope of reuniting after death:

> Mrs. B.: Just for him to be comfortable.
> Mrs. C.: It would be nice if he's here in July for our anniversary.
> Mr. A.: ... the hope, that eventually you're going to be reunited.

The spouses of patients in the uncertain group hoped for a miracle, cure, or prolongation of treatment effect; whereas, the spouses of patients in the inevitable group hoped for more time, limited short term goals, or for a spiritual eternity together.

Helping Work

The goal of spouses' helping work was to protect and care for the well being of the patient and family. Helping work involved providing physical care for the patient, protecting the patient from physical injury, preserving the patient's feelings, providing for the patient's emotional well being, and maintaining the patient's sense of self worth. In order to carry out this work, the spouses used a number of resources. These resources included information from professionals about what to expect from the disease treatments, and information from friends and family about such topics as diets. One spouse explained that God was her source of strength and that she prayed often for strength to manage and for her own health to remain good. The resource of a positive attitude was cited as very important for some of the spouses (3/7). They felt it was an important part of helping their husbands and wives.

Generally, spouses of patients in the inevitable group were more involved in providing physical care:

> Mrs. B.: Like I said, there's not much you can do about it except keep him comfortable as you can, try to get him to eat as much as you can.
> Mr. A.: I watch what she is eating and not eating, things of that nature. If I know she's suffering I tell her to take something (medication).

Spouses of patients in the uncertain group were more involved in providing psychological support than in giving physical care:

> Mrs. E.: Some days I get kind of depressed and I just got to try and keep up for him, so I think, at least I keep thinking, well I can't get sick.
> Mr. F.: I plan so she's not alone and take steps to remove stress.
> Mr. D.: Sometimes she is depressed and I have problems to try and get her out of it.

Maintaining a role for the patient was more a function of spouses of patients in the inevitable group than it was for spouses whose husbands or wives were members of the uncertain group. This was accomplished in a number of ways, such as having the patient pick out curtains for a new addition to the home, encouraging participation in decision making through having the patient continue to control the money used for household expenses. Mr. A., whose wife was a member of the inevitable group, stated his approach: "I refuse to take over totally at this time for obvious reasons because I think she still has to have something to do and something to keep her mind on".

An important part of helping work for both groups of spouses was to ensure an atmosphere where the patients could function as normallly as possible:

> Mrs. B.: It's better here (home), he can get up and walk around and go for a drive if he wants.
> Mr. F.: ... we just take steps to completely obliterate

> that part of our life that would cause any stress, so that M (wife) can think about only herself and function back as a normal person again.

All spouses had a protective role to perform for the patients. The scope of protection ranged from preventing physical injury to watching for the insensitivity of others toward the patient:

> Mrs. B.: When I leave, I make him promise to stay in bed until I get home, I worry he will get dizzy and fall.
> Mr. A.: It's just that it was too much (company) in too short a period of time for her, I don't think that was good.
> Mrs. G.: He (patient) has given so much, now when he needs their support it's not there.
> Mrs. B.: I like them (friends) to come over and visit but not for long though. It tires him out too much and I'd rather that they leave their kids at home.

The scope of helping work ranged from monitoring the patient's physical needs such as food, rest and pain relief to watching for the patient's psychological reactions such as depression or giving up. The spouses attempted to manipulate the physical environment and people within the environment in order to make life for the patients as comfortable and as meaningful as possible.

Surviving Work

The goal of surviving work was to "carry on" or "hang on" during the periods of either relative disease stability or disease progression in the patient's life. The focus of

surviving work changed depending on whether the spouse's husband or wife was in the uncertain or the inevitable group. Spouses of patients in the uncertain group were concerned with managing the strain of uncertain outcome in their loved one's illness. For spouses whose husband or wife was a member of the inevitable group, the focus was on managing the strain of watching their loved one's progressive illness.

Regardless of to which group their husbands and wives belonged, all spouses needed a variety of resources in order to manage their surviving work. Information was one of the most necessary resources for all spouses, but the amount of information available to spouses differed according to patient group. Spouses of patients in the uncertain group were included in discussions with the physician and felt that they had the necessary information. This was not always the case for spouses of patients in the inevitable group; these spouses described more dissatisfaction about their ability to obtain information. This will be discussed in more detail later in this section.

In addition to information, surviving work required that the spouses utilize every resource available to them. The spouses relied on family and friends for interpersonal help such as "someone to talk to" and social diversion. Family and friends also contributed support to the spouses through telling encouraging stories about other people's success with cancer. In

addition, they assisted the spouses with the patient's physical care through referrals and recommendations. One spouse's sister made a referral to a doctor who prescribed vitamins for the patient and the spouse felt: "That's the only thing keeping him going right now". Family and friends recommended such things as holistic medicine care approaches, relaxation techniques, and a hospital palliative care unit.

Spouses made use of their own internal resources for surviving work by keeping their minds occupied on other things and by keeping physically busy. Religious practices and faith in God were other resources which spouses used for surviving work. Surviving work required the greatest variety of resources. It was the aspect of work most discussed by spouses.

Some aspects of surviving work were the same for all spouses regardless of patient group; some aspects were different depending on which group the spouse's husband or wife was a member. Similar areas of surviving work included: talking to someone about the situation, distracting themselves from the problem of the illness, and adjusting to changed life plans. Areas of surviving work which differed, according to which group the husband or wife belonged, were how the spouses viewed the future, the degree to which they expressed the need to be introspective, and their access to information.

Similar aspects of surviving work are presented first,

followed by those aspects which differed according to patient group.

Similar Aspects. The majority (6/7) of spouses found it helpful to be able to talk about their feelings and reactions to the situation:

> Mr. A.: I'll ta[illegible] to M (friend) or to my kids and to my wife, she'll be the first one I go to at any time.
> Mrs. E.: It's just nice to be able to talk to somebody.
> Mrs. G.: I have a girlfriend I can talk to, once I spill things to one person, I'm ok.

All spouses reacted in a similar manner concerning their need to get away from the emotional and physical strain placed on them by their husband's or wife's illness. There were times when they needed to be distracted from the demands of the disease:

> Mrs. C.: I need to live a normal life. I cannot be glued to this problem, this illness. I can't be.
> Mr. D.: You decide you'll do something and get out of it (the thought of illness) and get busy and do something or go somewhere, and it helps to keep moving, keep active.

All spouses achieved distraction through keeping physically busy either within or outside the home. Keeping busy included activities involved with maintaining a job, shopping, and keeping a house. These everyday activities took on special importance for spouses by allowing them to think of other things.

Another component of surviving work required an adjustment to changed life plans. Spouses' approaches to these changes ranged from beginning to think about what lay ahead to taking active steps to make the necessary adjustments immediately:

> Mr. D.: The future is clouded. It's going to be quite hard on both of us.
> Mr. F.: The thinking that's most in our minds is to straighten out our lives so that we're not subject to those influences (stresses), so that we can recover.

For one spouse who had been ill and thought he would die first, his wife's illness was a major adjustment and much of his interview was taken up with descriptions of how difficult it was for him to find out that his plans to leave his family well looked after were now in doubt. A great deal of his energy was being used to adjust to this change in life plans:

> Mr. A.: I was quite sick myself years ago and I was not supposed to live, so this is a role reversal. I didn't believe she was sick when we just found out, then it became anger. It meant a shift in me and I had to change my outlook.

Differing Aspects. Some components of surviving work differed depending on the group to which the patient belonged. These differing components were the spouses' view of the future, their degree of introspection, and their access to information.

In addition to emotional concerns about their own immediate

survival, the spouses also had to face survival in the future. Spouses of patients in the uncertain group expressed a sense of a future which involved the patients. These spouses were determined "to make the best of it" and enjoy their time together:

> Mrs. E.: Just live day to day and enjoy it.
> Mr. D.: I guess you try and make the best of it while you're here.
> Mr. F.: You know, you never think about your life ending until some specific thing says you may or may not have very much time left. So we decided we better make the most of it.

In contrast, spouses of patients in the inevitable group were not able to face the future as directly. Two spouses could not describe what they would do after the patient died, although they acknowledged that death was close:

> Mrs. B.: I try not to think about it (husband's death).
> Mrs. A.: It's her loss that I'm going to have to worry about and that I don't know. I don't know. I can't appreciate losing her. I'll be honest with you I don't know what I'll be like when that happens.

Spouses whose husbands or wives were in the uncertain group, were anticipating a future which they saw might include suffering: "It's going to be bad when the pain comes". Spouses of patients in the inevitable group however were face to face with suffering: "It's hard to see him suffer". These spouses

had difficulty looking at their ultimate loss: "I'll cross that bridge when I come to it".

There was also a difference in the degree of introspection described by the spouses. Spouses of patients in the uncertain group discussed more introspective thinking:

> Mr. F.: I spent more time by myself in the last year than I ever have before so I had more time to think about those things (life and death issues).
> Mrs. G.: I realized my strength was from within. Whatever resource you have in the world ... it's yourself, your strength comes from within.

The spouses of patients in the inevitable group did not discuss being introspective. However, if they were not able to face the ultimate loss and if they were "trying not to think about it", then it would not be surprising that they would also not engage in introspective thinking.

Information was an essential resource used by all spouses in their survival work. There was a difference however in how the information was obtained by the spouses of patients in the uncertain group compared to those whose husbands or wives were in the inevitable group. Spouses and patients in the uncertain group went to the doctor together, and there was more evidence of a team approach in deciphering the information than was evident with the spouses and patients in the inevitable group. Spouses of patients in the uncertain group described the following

approaches to information gathering:

> Mr. D.: The doctors explained the facts to us.
> Mr. F.: We went to the doctor. They give you facts and then it's up to you what you do with them.
> Mrs. G.: We found it was essential to go together.

In contrast, spouses of patients in the inevitable group were not allowed by the patients as much access to information nor did these spouses get as much information:

> Mr. A.: I'm quite sure she did know far more about them (facts about the illness) than I ever did, but she never sat down and explained any of these things to me.
> Mrs. C.: He had been going (to the hospital) all on his own. I'd ask to go along but he didn't want me. So I didn't go. One time I went to his doctor and had a long interview with him.

An exchange between Mr. and Mrs. B. also revealed this lack of giving information.

> Mr. B.: At the beginning, I wouldn't take her in the examining room with me so she really had no idea about how bad it was. Then I stopped and thought, and said "this is going to be hell for her not knowing" so I started saying to her "come with me".
> Mrs. B.: I knew more or less what was going on but he'd tell me most of it, didn't you?
> Mr. B.: Well, I'd tell you what I wanted you to know.
> Mrs. B.: Oh.

For spouses, the work of surviving ranged from not thinking about it, keeping busy, rearranging life, and trying to face the

future. Spouses of patients in the uncertain group approached the situation with an attitude of "carry on" with life activities; spouses of patients in the inevitable group approached the situation with an attitude of "hang on" until the end.

Preserving Work

The goal of spouses' preserving work was to keep the family and its memories intact, despite the threat that cancer had brought into the home. The focus of the work changed depending on the group to which the patient belonged. Spouses of patients in the uncertain group concentrated on creating memories, enjoying family life and the patient, and changing their priorities. Spouses of patients in the inevitable group concentrated on reviewing memories, healing past hurts, and making the most of the time left.

The major resource which supported preserving work was the spouse's own attitude and determination to make the best of the situation and enjoy the time the family had left. As well, the need to be a parent to the children as well as a caregiver to the patient, prevented spouses from giving in to despair.
Their love for their husbands and wives was also a resource which enabled them to engage in preserving work, especially the work of keeping family memories intact.

Preserving work in relation to memories differed according to whether the patient was in the uncertain or the inevitable group. Spouses of patients in the uncertain group worked at creating memories; whereas spouses of patients in the inevitable group reviewed or kept intact previous memories. Mr. F. and Mrs. G. were spouses of patients in the uncertain group; Mr. A.'s wife was in the inevitable group:

> Mr. F.: We took more trips as a family.
> Mrs. G.: If I see L (husband) doing something in the garden, that is a moment to remember. I find myself saying "I'm enjoying this, this is a cherished moment". Before, it was just part of the ongoing.
> Mr. A.: One thing that I will say that cancer has done is it has given us a chance to recount those memories and enjoy them ... we redid all of our photograph albums. Probably we would not have done that or shared with our kids.

Spouses whose husbands or wives were in the uncertain group described changing their priorities:

> Mr. D.: We spent longer time on our vacation, we probably would not have done that before.
> Mr. F.: I made up my mind to spend more time with M (wife) and cut out extra curricular things.

One spouse of a patient in the inevitable group discussed her intent to make amends for past hurts:

> Mrs. C.: I've got lots of amends to make.

All spouses, regardless of patient group, worked at keeping the "family fiber" intact, especially when children were still at home:

> Mrs. G.: I didn't want the children to be affected by my own emotional state. We sat down and we had a game plan that we were just going to conduct life normally for as long as we could.
> Mr. A.: Normally she (patient) would be the one that would discuss things with the children, but the relationships have now changed in that the caring one is going to have to be me as opposed to her.

Spouses assumed as much of the responsibility for living as possible, meeting the needs of their ill spouse, and the demands of their well children. Spouses also felt a responsibility to preserve the time the family had left together in order to enjoy the time they would have with the patient; to remember the pleasant memories of the past; and, to create memories for the future, the unspoken future which would not include the patient.

Taking Stock Work

The goal of spouses' taking stock work was to review their pre-illness life with the patient. Spouses' responses centered on the positive and regretted aspects of their shared life, and included a review of the patient's character. There was no difference according to patient group in how much the spouses discussed their shared life or the patient's character. In

addition, spouses' focus did not change according to patient group. Resources which supported this work were the relationship with the patient, the spouse's mental activities of reliving their shared life, and talking about the patient to others.

Spouses reviewed their relationship with the patient from a positive vantage point:

> Mr. A.: You know, we've had a substantially good life and good relationship, never ran around with anyone else. We've never had any of those problems.
> Mrs. C.: There has been a lot of ups, more ups than downs, and he has been an excellent provider, an excellent father.

Life reviews also contained elements of regret both for personal relationships and for choice of life style:

> Mrs. C.: I've hurt him, but he's hurt me too.
> Mr. A.: I'm losing a partner that shared more of her life with me than I did with her, I think. She was more giving than I was.
> Mr. F.: If you had your life to live over again, there are some things I would steer us away from that were potential trouble spots.

Discussions of the patient's character were particularly important to four of the seven spouses. Most reviews emphasized the patient's good points rather than providing a balanced view which would include some negative aspects:

> Mr. A.: She's best off in the world when she is thinking

about somebody else. She doesn't care about herself, but she cares about herself as far as it affects other people.
Mrs. G.: He's very accepting, very calm. He has something very special.

Only two of the seven spouses included comments about the patient's weaker character traits:

Mr. D.: She does not have much endurance, unfortunately.
Mrs. C.: He does not understand our teenagers.

Taking stock was part of what the spouses did to manage the situation; it allowed them to look at what they had, not what they were losing. It was more important for some spouses than others to discuss the patient's character and their life together. Two spouses from the inevitable patient group and three from the uncertain patient group contributed the most to this category of work; the remaining two spouses did not provide as much information about the patient's character. Of the spouses who did not spend as much time in the interviews on their life together or the patient's character, one indicated that she "was not a good talker"; the other spouse, after making a comment about the patient, stated "I probably shouldn't discuss this because it's our inner secret". However, for all spouses, there was energy directed toward a life review and an evaluation of the patient's character which emphasized positive aspects.

Summary

Spouses, like patients, had work to do in order to face the advanced cancer diagnosis in their loved ones. Patients faced a different task depending on the group to which they belonged, spouses' tasks did not differ as much according to patient group. Although some differences did exist, they were not as clearly defined. Spouses' tasks differed in the degree of uncertainty they faced concerning the eventual outcome of the patient's illness and in the length of time during which that outcome would occur. Patients' work was mainly directed toward what they had to do to face their major task; however, the spouses' work was directed mainly toward what they had to do for the patient and the family. A major area of work for spouses centered on survival during this demanding time.

When children lived in the home, a portion of the spouses' survival work had to do with making the situation as painless as possible for the children. In situations where the children were grown, whether living in the home or not, they became a resource to spouses and supported their survival work.

The work focus for spouses did not display as much difference according to patient group as did the patients' work focus. Generally, spouses did not display a narrowing down of focus nor did they become more integrated. As patients became more limited physically, they described very concrete plans for

living the rest of their lives and outlined specifics of how they were dealing with all of the ramifications of a cancer diagnosis. Spouses, however, described a work focus within their various areas of work, closer to that of patients in the uncertain group. Specifically, the spouses preferred not to face the inevitability of the patient's death and were, with the exception of one, not certain about how they would manage following the patient's death. Spouses' descriptions were of possibilities not inevitabilities.

Fit Between Patient and Spouse Work

Both patients and spouses engaged in work which allowed them to manage the diagnosis of advanced cancer. Each type of work, for both patients and spouses, had a goal and a focus, and required the utilization of energy and resources for the goals to be accomplished. Patients described six types of work and spouses described five. A different goal was identified for each type of work. Spouses' goals for each type of work remained the same regardless of which group the patient belonged. However, the focus and progression toward meeting the goals were different for both patients and spouses depending on which group the patient belonged.

The focus of the patients' work was different depending on whether their task was to face an uncertain outcome or inevitable

death; spouses' focus also changed according to which task their husbands or wives had to face. Generally, spouses' focus did not differ, according to patient group, as much as the patients' focus did. Spouses described more uncertainty even when their husbands or wives were able to describe the inevitable outcome. Reported in the following section are the results of comparing the types of work of patients and spouses. The comparison includes a review of the objects of their work, and the similarities and differences in work type and resources for both patients and spouses.

Patient and Spouse Work

Patient and spouse work was compared according to the object of the work. The work is directed toward these different objects: self, others, and disease. Secondly, types of work which showed key similarities and differences are reported. Finally, differences in how patients and spouses generally viewed the future are described.

Objects of Work. Patients' work was mostly directed toward self, whereas spouses' work was directed toward others. Patients' work of hoping, daily living, and controlling were concerned with self and a portion of maintaining work was also involved with self through the patients attempting to maintain

the support of others. Surviving work was the one type of spouse work which clearly focused only on self, although a portion of other types of work would support self as well as help others. For example, taking stock work helped the spouses prepare themselves for loss. Generally, however, spouse work was directed to others. For example, hoping, helping and preserving work were directed to the patient and family. In contrast, the object of patients' work was on others only in preparing work. The goal of preparing work was to plan ahead to equip the family to manage following the patient's death. As well, a portion of maintaining work was concerned with helping others through the patients purposefully adopting a "positive" or "serene" attitude which they felt served to calm the family.

Patients approached the disease directly and had a specific category of work dealing only with the disease. The goal of fighting work was to do the best they could against the disease. Spouses, however, could only approach the disease indirectly through the provision of emotional and physical help to the patients and through hoping for a desirable outcome.

Work Similarities and Differences. With the exception of one type, work was different for patients and spouses. Hoping work was the only type of work which was the same for both patients and spouses, and it also had the same goal and focus.

The one area of work that predominated for patients and spouses differed for the two groups. For patients, controlling work predominated; for spouses surviving work was discussed the most. Though the types of work differed, there were similarities in what patients and spouses wished to achieve. Patients desired to control "self" in the situation and spouses desired to "hang on" or "carry on" during the situation. Both of these areas of work were directed toward what the individual could do on her/his own behalf to manage or control the emotional reactions experienced as a result of advanced cancer.

Some of the work, although different for patients and spouses, seemed to support each others work. For example, patients' daily living work was supported by spouses' helping work. Spouses, by accommodating a continued role for patients and by being positive, allowed patients to live as normal and meaningful lives as possible. In contrast, some of the patients' and spouses' work resulted in conflict. If spouses, in order to survive, must "not think about it" and patients, in order to prepare the family, must talk about what to expect and how to "take down the sheers for cleaning", then there are difficulties for both patients and spouses. Generally, spouses were aware that they must make the compromises and accommodate to patients' needs, not their own.

Time Perspective. A difference in how time was viewed existed between the patients and spouses. Generally, patients' descriptions of particular types of work were more future oriented than were spouses' work descriptions. Spouses of patients in the uncertain group described more future plans in their work than did spouses of patients in the inevitable group. However, patients, regardless of group, provided more descriptions of what they planned for the future. This was evident in hoping, preparing, maintaining, and fighting work.

Spouses described more efforts to manage the present and to remember the past. Spouses' work of preserving and taking stock are examples of the different time perspective that existed between patients and spouses. Patients did not describe as much involvement in the past except where they described the source of their inner strength, and where they described their childhood and past death related experiences. Overall, the basic difference in the time perspectives of patients and spouses was that patients were more oriented in the present and future, and spouses were more oriented in the present and past.

Patient and Spouse Resources

Both patients and spouses used a variety of resources to help them handle the diagnosis of advanced cancer. However, spouses used resources from a greater variety of sources than the

patients did. Patients' main source of help was from within themselves; whereas, spouses relied more on outside support. Patients' main outside help came from their spouses; the main source of outside help for spouses came from family and friends. Generally, it was enough for the patients to be with their spouses, however, spouses expressed more need for contact with others and to be more active socially.

Summary

Patients engaged in six types of work and spouses engaged in five. Each type of work had a goal and a focus, with the focus changing according to patient group. In addition to a goal and focus, patients' and spouses' work was directed toward an object. Three objects were identified: self, others, and disease. Patients' work was predominantly directed toward self and spouses' was predominantly directed toward others. Patients were able to direct one type of work toward the disease; spouses were only able to deal with the disease indirectly by helping the patients.

Only hoping work was the same for both patients and spouses. Some patients and spouses work supported each others efforts and some work types resulted in conflict.

Patients and spouses had different perspectives on time. Spouses concentrated on the present and past, and patients looked

more to the present and future. . .

Resources were vital to both patients and spouses, but spouses used resources from a greater variety of sources than patients did. Patients described more need to rely on spouses than on anyone else.

Couple Responses

A final portion of the last interview was conducted with the couples together. The intent of this interview was to elicit their responses to questions dealing with the effect of the situation on them as a couple, to discover what, from their experiences, they might like to share with health care workers and others facing the same situation and to allow them the opportunity to comment on their reactions to taking part in the interviews. Their responses to each of these aspects are described in the following sections.

Effect of the Disease

Despite the potentially dreadful physical effects of a diagnosis of cancer on individuals, respondents indicated there were also positive effects on their personal life with others and a heightened sense of appreciation for the "small things" which can otherwise be overlooked. Positive comments most often given by both patients (6/7) and spouses (4/7) had to do with their

perception that they felt closer to one another since the diagnosis. In addition to feeling closer, there was also a sense of deepened appreciation for their life together and for life in general. Both patients and spouses remarked on their enhanced sense of what was valuable and important in their lives:

> (Spouse)
> Mrs. G.: I could see nothing but bad at first, but I have worked through that I think. It's unfortunate that things like this have to happen to increase awareness so much, but I would say we're more perceptive, and express our love more freely and appreciate time, even though we think we've always done that.
>
> (Patient)
> Mr. G.: It has heightened things. It makes you aware of some of the aura (of life). We take notice of the smaller things.

Participants also reported that the effect of the diagnosis on the family was also positive in that it served to draw the children closer to one another:

> (Patient)
> Mrs. A.: The children have become closer to one another. Without being morbid about it, they're forever laughing and joking.

Telling the children and watching the children's reaction to the situation, however, was reported as being very difficult for three of the four couples who still had children at home. They discussed the trauma that their children experienced initially,

but the parents could now see some positive responses in the children as well:

> (Spouse)
> Mrs. G.: I mentioned to you how hard it was to talk to the girls. One had a disastrous year scholastically ... doing a lot of daydreaming. But right now she's just sailing. We're doing a lot of sitting and laughing now.

Two spouses reported negative effects of the situation were that their freedom to interact outside the home was limited and one spouse stated the disease "added a bit of worry". Overall, however, responses indicated that some of the effects of the diagnosis were positive, resulting in an expressed determination to "enjoy life", "make the most of our time together", "be more open to express affection" and to "get our priorities lined up".

Recommendations to Health Care Workers

All couples wanted health care workers to give them information which they called "the truth" or "the facts". In addition, couples appreciated staff who displayed knowledge, patience and sensitivity in their approach to care of the patient or families. Two couples expressed concern that AIDS research not replace attention to or remove money from cancer research. One patient expressed the need to be able to talk to someone "who could face up to it" until such a time when her family and friends "came around to the point that they could talk because

they just couldn't in the beginning". Generally, couples looked to the health care worker for skilled care of "machines" and "I.V.s" and to provide answers to their questions. Couples appreciated it if, in addition to meeting the practical care needs, the health care workers met those needs in a friendly, concerned manner.

Recommendations to Other Couples

Overall, couples indicated that it was important to "appreciate the time", "enjoy each day", "live day to day" and "do the best you can". Two couples felt they really could not recommend anything because they felt everyone was different. One spouse expressed a sense of helplessness in the situation and therefore could not begin to tell anyone else how to manage. Having and sharing the facts and being positive and patient were also included as recommendations to other couples experiencing similar situations.

Effect of the Interview

Of the seven couples, all patients (7/7) and five spouses found the process of participating in the study helpful. The response by Mrs. A. typified patient comments about the effect of the interviews:

> Mrs. A.: If anything, it helps. You talk. You ask a question, you bring out things you maybe hadn't thought about or were thinking about, but not bringing forth.

Some patients (4/7) commented on the importance of creating more understanding with the hope that future patients and their families would benefit. Another effect of the interview was to give patients reassurance that health care workers were interested in how cancer affected them and their families:

> Mr. E.: It's nice to know that somebody has interest ... so that makes us feel better too - we are not caught in a group, cause there's nothing worse than feeling like a number and forgotten.

Although the effects of participating were positive for most respondents (12/14), for two patients and one spouse the interviews also had a disturbing, as well as a positive effect. For these patients, it was disturbing to remember the initial diagnosis with all of the events which were a part of that time, such as "telling the children". Facing the future was the other disturbing issue of which patients were reminded during the interviews. The spouse who reported a disturbing effect from the questions because they caused him to think of the future loss of his wife, went on to say the interview was "maybe disturbing at the time but not in the results". Two spouses reported that taking part in the interviews had no effect on them at all; one prefaced this remark with the statement "what can help?". Nearly

all patients and spouses found it helpful to have the opportunity to talk and to feel that they were contributing in some way to an improved understanding of the disease.

CHAPTER V

DISCUSSION OF RESULTS AND IMPLICATIONS

The purpose of this study was to identify what resources the spouse/caregiver and the patient used to manage the care of a patient with advanced cancer in the home. In addition to identifying the type of resources used, the sources and usefulness of these resources were also described. Results revealed more information than whether resources were useful or not, which was the researcher's original intent. The results described the purpose that resources served for patients and spouses. Furthermore, the concept of patient and spouse work was developed. Findings also resulted in a different classification system for resources than was originally developed and used as a basis for the semi-structured interview schedule.

This chapter includes discussion on: 1) major resources used by patients and spouses, 2) resource meaning from the concept of work, 3) implications for practice and research; and, 4) limitations and strengths of the study. The first section on major resources used by patients and spouses includes a discussion of the following specific resources: physical, informational, interpersonal, and spiritual. Resource types are discussed first and then sources are elaborated on for both patients and spouses. In the second portion of the chapter, the

concept of work, as it is described in this study, is compared to other areas of work identified in literature. Also, other concepts such as coping and anticipatory grief which are related to work are discussed. Third and fourth sections include discussions of the implications of the findings for practice and research, and limitations.

Resource Types: Patients and Spouses

Resources used to manage chronic illness have been classified in a number of ways. Instrumental, emotional and informational classifications were used by Unger and Powell (1980) as a way of conceptualizing individual resources. Lazarus and Folkman (1984) included recognition of what the individual contributes by identifying such things as health and energy, beliefs, and problem solving abilities as potential resources. The classification suggested by Pearlin and Schooler (1978) of social and psychological resources aligned closest with the internal and external classification system identified in this study. Pearlin and Schooler's social resources included interpersonal networks of people who could assist but did not directly identify tangible resources. Further division, in this study, of external resources into physical and interpersonal helps to identify such resources as medications, information, and help with daily living activities so necessary for an individual

with advanced cancer.

Internal resources of character, faith, attitude, and self awareness identified in this study have also been alluded to by Pearlin and Schooler (1978). They identified psychological resources as including personal characteristics people draw upon in time of need. Initially, the classification of physical, emotional, informational, and religious resources was used in this study to develop the focussed interview guide. However, when data were analyzed, a different resource classification evolved. This is possibly a moot point; however, it does point out that qualitative research must be approached without preconceived ideas, or at least with the recognition that initial ideas may not reflect the subjects' perceptions of the issue.

Findings indicated that a number of specific resources were important to patients and spouses. The following section provides elaboration on physical, informational, interpersonal, and religious resources used or sought by patients and spouses dealing with advanced cancer at home.

Physical Resources

Resources to manage pain were most important to both patients and spouses. One patient in this study questioned if "life was worth it" when his pain was at its worst. Once pain was managed, at least to a degree, activities of living were once

again something to be sought. Medications were the most common resources used to manage pain, although some patients also supplemented with relaxation techniques. For spouses, fear of future pain or watching pain in their loved ones was traumatic. In addition, the presence of pain caused relational difficulties. One spouse reported pain was largely responsible for the patient's display of anger toward the spouse. Resources next in importance for spouses were anything which assisted with eating and nutrition, such as, vitamins and healthy foods. Comments of "make sure she is eating" and "try to fix him special foods" were made by spouses of patients in the inevitable group. Paramount concern for meeting physical needs has been noted before (Rose, 1976; Edstrom and Miller, 1981; Wright and Dyck, 1984; Hinds, 1985). Resources which allow adequate control of physical symptoms are vital to allow patients and spouses to enjoy the time they have with each other.

Informational Resources. Informational resources were important for emotional adjustment in patients and spouses and for effective physical care of patients. Types of information received included information about the disease, how to meet the care and comfort needs of the patient, and stories of positive outcomes of treatment in others. Patients wanted to know "the facts" and "the truth" about their disease and its progression.

For patients in the inevitable group, getting the facts and the truth meant receiving bad news. Not receiving good news meant these patients had to find another way to be positive about the situation. Patients in the inevitable group accomplished this by seeing that there were others who were worse off than they were. Two patients who were told that their cancer was terminal, chose to make up their own minds about the outcome. One, when told his cancer was terminal, responded by saying "to hell with you, I'm going to live until I can't stand no more". The second patient stated he did not find being told his cancer was terminal very helpful at all and concentrated instead on "when I will get better".

For patients in the uncertain group, good news was that the treatment was working or that the cancer was under control. These patients were most satisfied with the type of information they received about their disease. The amount of disease patients have may influence their need for and reaction to information. Derdiarian (1986) in her study of 60 recently diagnosed cancer patients' information needs found that patients with local disease tended to need more information than those with disseminated disease. In addition, the seriousness of the disease may also have an influence in how actively patients pursue information. In their study of 74 cancer patients receiving treatment for life-threatening illness and 72 patients

with non-life-threatening illnesses, Feifel, Strack, and Nagy (1987) found that patients with life-threatening illnesses used more confrontational and active information seeking behaviors than did patients with a non-life-threatening illness.

In the present study, one patient in the inevitable group was angry about not being informed about the extent of his disease at some point in his experience with physicians involved in his care. He felt his decision making had been severely hampered. Degner and Beaton (1987) also reported this ongoing problem that patients and families have of obtaining information from health care professionals. In their qualitative study which utilized participant observation, interviews and document review in 14 health centers, Degner and Beaton reported that "lack of information sharing with patients and families represent a major problem in the field of health care" (p. 137). They go on to say that the information received by patients and families was what the health care professionals chose to share, not necessarily what was asked by patients and families. Another patient in the present study, who was a member of the inevitable group, indicated "if you don't ask nothing is going to be volunteered". Questions arise as to whether health care professionals consciously or unconsciously share information more openly if it is good news than if it is bad news, and whether patients do not accept bad news and then feel as if they have not been told.

All spouses of patients in the inevitable group reported frustration in meeting their own informational needs. They were not told by their husbands or wives even though in two cases spouses felt that the patients knew. One spouse found out during the interview that she had not been kept informed by her husband. All spouses in the uncertain group reported going with patients to see the doctor and were satisfied with the type and amount of information received. The factors which may contribute to this lack of information sharing by patients in the inevitable group were not looked at in this study. A longitudinal study would be required to explore whether information sharing behaviors changed as a result of worsening disease or whether personality factors or the patients' desire to protect spouses played a role.

Information supplemental to the medical approach to care included: vitamin therapy, holistic medicine techniques, and referrals to other physicians. One spouse had received a number of book suggestions from friends dealing with how to cope. Not all of these suggestions had positive results. After reading one of the recommended books, the spouse was distressed to read that stress and diet caused cancer and she felt that this indicated she had in some way contributed to her husband's illness by not giving him a healthy environment. This was a direct attack on her attempts to provide a healthy diet and a good environment for her family; as a result she was discouraged rather than helped by

the information. On the other hand, positive stories about how other people lived with cancer were an encouragement to two couples. One spouse reported that hearing from an acquaintance about how he managed cancer in his family was helpful. Hinds (1985) noted as well that most of the help with patient care and support to families came from their relatives and friends.

Informational resources used by patients and spouses were related to disease, care and psychological comfort. The amount and type of medical information was not always as the patient would have liked. Two patients in particular were not satisfied with the amount of information provided. However, the rest of the patients felt the information given was adequate and complete. However, being told that his disease was terminal was reported as not being very helpful for one patient leading to the question of how and when to tell people bad news. Spouses were not always kept informed by patients, but it was not clear from this study if this was an established way of relating in those cases or if seriousness of the illness influenced the amount of information given to spouses by patients.

Interpersonal Resources

Relationships between spouses and patients comprised an important interpersonal resource. The supportive influence patients' responses can have on family caregivers has been noted

in writings dealing with care of the elderly. The results of Hirschfeld's (1983) study of 30 family caregivers of demented elderly patients, showed that caregivers continued to live with and care for their elderly relative when caregivers found satisfaction in their relationship with the patient. The results of a study of cancer patients also showed that confident and cooperative patients were among the factors which allowed home care for the terminally ill (Parkes, 1978). The results of this present study showed that in situations where patients were depressed or angry, spouses reported difficulty in trying to help them. One spouse went on to say "I have to get away from this illness". Patients acknowledged the role they played in their family's adjustment. Four patients elaborated on the attitude they assumed to help their families be around them and accept the illness. A positive attitude on the part of the spouses toward the situation was also an important interpersonal resource for patients. One patient reported that although she did not know if her husband was really as positive as he portrayed himself to be, it was very supportive to feel he was positive about her disease outcome. Thorne (1985) found in her study of eight families made up of patients, six spouses, three adult children and three other kinfolk, that strategies which support normalcy were valued by families and one aspect of normalcy was a positive attitude.

For spouses, another aspect of interpersonal resources dealt

with their need to be able to discuss the situation with someone other than the patient. Talking it out with friends was especially important for four of the spouses. In Hill's (1984) study of 50 family caregivers of elderly relatives, participants also described the need to have someone to talk to who was objective.

Religion

The role of religion, spirituality or faith was not explored in depth in this study, but some information was obtained which warrants further investigation. Spouses volunteered that there had been a change in their approach to religion. One change was to become more philosophical: "I think more about life and death issues". Others reported an increase in religious activities such as praying and going to church. Patients, unlike spouses, did not discuss their use of religious resources as much; however, two patients reported that religious activities were not used, but then stated that "faith was something else". Aspects of "something else" were not investigated in this study. A spiritual sense of connection with the universe was reported by two other patients as supportive because it allowed a way to make sense of the situation. One patient's universe had God in the center; the other patient's universe had nature in that position. One patient felt that she would grow in spiritual depth and

understanding as a result of her illness. She reported that she had not as of yet, but she was seeking this growth. She reported she had observed spiritual serenity in a dying North American Indian lady whom she had met prior to her illness and she would like to achieve this serenity herself now that she was dying.

Although, in this study, spouses reported using more religious resources than patients, other researchers report an increase in the uses of religious resources by patients when they are aware of a terminal illness (Reed, 1986; Sodestrom and Martinson, 1987). These researchers, however, did not study family members. Reed (1986) used the Religious Perspective Scale and an Index of Well Being with 57 people who were terminally ill and with 57 healthy adults matched by age, gender, education, and religious affiliation. The results of her study showed that terminally ill patients reported significantly greater religiousness but this increased religiousness did not show the expected positive correlation with well being. Sodestrom and Martinson (1987), in their study of the perspective of nurses and patients on a patient's spiritual coping strategies, reported that patients who knew they were terminally ill used more religious resources such as prayer, reading the bible, and watching or listening to religious programs than did patients who were not aware of their prognosis. The aspects of religion, spirituality, and faith as resources warrant further study.

However, these are not resources which can be "packaged" and given to patients and their families. If they are resources that patients find helpful, then professionals should at least do no harm, by either discrediting the resource or by forcing the spiritual resource onto unwilling patients and spouses. In this present study, for example, one spouse was uncomfortable with questions dealing with religion as a resource and stated a preference not to answer the questions. In contrast, two other spouses stated that their faith in God was a strength for them and allowed them to be hopeful for a cure or spiritual reuniting following death. Even though Bell (1985) notes that spirituality is a mystery and suggests "it is the energy within each person that struggles for meaning and purpose in life", perhaps study of this aspect of life would lead to better understanding of how health care workers can best help patients and families in this personal part of their lives.

Sources: Patients and Spouses

Sources of external resources for both patients and spouses were professionals, family, and friends. The source of internal resources for patients was their character, upbringing and past death related experiences. Degner and Beaton (1987) also noted in their study that the knowledge families took to a cancer situation was what they had obtained from previous health care

and life experiences.

Physical Resources

Generally the source of physical resources were health care professionals, such as physicians, nurses, and physiotherapists. These findings have also been reported by others in their review of home care (Zajac, 1985; Gotay, 1984). The source of medications as a physical resource was physicians. Other physical resources, such as canes and bath tub helps, came from the local cancer institute.

Informational Sources

Doctors were the source of information related to the disease, its treatment, and prognosis. Cartwright, Hockey and Anderson (1973) also found that the family doctor or the hospital doctor were the sources of disease related information. Couples, in the current study, reported that nurses were their informational source for specific care techniques, such as infusion devices. Other researchers have indicated that nurses were not seen as a source of information by patients (Dodd, 1984; Mitchell and Glicksman, 1977). Dodd's study however dealt with patients undergoing radiation therapy and possibly nurses were not seen as being responsible for radiotherapy, and therefore, patients would not expect information related to this

technologically complex therapy from nurses. On the other hand, the patients in Mitchell and Glicksman's study were outpatients and patients in their study reported seeing the nurse as someone who "ran the examining rooms and helped the physicians". In contrast, results of the present study showed that nurses were looked upon for specific care technique information. In addition, one patient stated that she talked to nurses about her disease and its seriousness until her family could "catch up" to where she was in dealing with the situation.

Supplemental information concerning care approaches other than those given to couples by the hospital personnel came from friends, acquaintances, and family. In this study, friends and acquaintances were reported as contributing nearly all information on paramedical care approaches, for example, information on vitamins, holistic medicine, and positive thinking techniques. A similar finding was also reported by Grobe, Elstrup and Ahmanne (1981) who reported that very few families learned from health care professionals. In this current study, acquaintances were usually people who were experiencing or had experienced cancer in their own families. Their information dealt mostly with stories of how they managed and the positive results of treatment. This type and source of support was also noted by Thorne (1985).

Interpersonal Resources

Patients looked mainly to their spouses as their source of support. Others have also reported that spouses play a pivotal role for patients with cancer (Northhouse, 1984; Wethingtra and Kessler, 1986). The patients in the present study, especially those in the inevitable group, wished to be with their spouses and immediate families more than with anyone else. In contrast, spouses of patients in the inevitable group reported need for greater numbers of people interactions and elaborated on the role friends and family played in their support. Both patients and spouses reported that the illness caused them to change their priorities for how and with whom they would spend their time. This was especially true for the patients and spouses who were members of the uncertain group. The result was that they took more time for vacations together and as one spouse put it, "cut out any extracurricular activity", which would take him away from his wife. Reports in the literature of isolation and lack of help from friends and family when someone is terminally ill (Giacquinta, 1977; Parkes, 1980) may have been a pattern established prior to the time when the illness became debilitating. Friends may have felt left out earlier in the illness trajectory and did not know how to assist when the illness worsened. Withdrawal of family members was not reported by the subjects of this study. If anything, the immediate family

(children) were closer since the illness, that is they visited more often and were reported as being more considerate to the patient. Others have also written that families report feeling closer (Slaby and Glicksman, 1985).

In the present study, only two examples of friends' withdrawal were discussed by patients. One patient felt that some of his friends no longer visited as often due to their concern for his fatigue level and for the fact that any noise they may make would cause him more pain. A second patient discussed an interaction which she had with two friends shortly after she had been diagnosed with cancer. She reported that her friends attempted to avoid her when they met in a shopping center. The friends were visibly uncomfortable and were relieved when she terminated the interaction. Subjects of the present study indicated that, there was some withdrawal of friends, but acquaintances with past cancer experiences either personally or in their families sought out patients and spouses to see if what they had learned from their experiences could be of help. Couples in the uncertain group changed their activities in order to spend more time together and this factor may lead to isolation later as the disease progresses. A second explanation for isolation later in the disease process may have to do with the lack of ability to get out of the home due to increased debility of the patient. An element of social restriction was noted by

three spouses, two in the inevitable group and one in the uncertain group. This was due to patients' lack of mobility and reluctance to be left alone. Getting out was an important issue for all spouses and patients in those situations where the disease had progressed to a point where it was limiting mobility.

Religious Resources

Sources of religious resources reported were clergy, priest, friends, religious icons in the home, and an internal belief system. Sodestrom and Martinson (1987) reported that the majority of 25 cancer patients identified family members as their spiritual source. Patients and spouses in this current study did not report that family members were a source of religious help; however, this aspect was not investigated in depth.

FIRM Results

An interesting finding from the results of FIRM was the fact that only one couple scored low on mastery and health scale, even though four patients were troubled with pain, weight loss, and decreased mobility. However, of these four patients, all were able to be up and about to some degree. It has been noted in a previous study that mobility may play a major role in patient's sense of well being. Reed (1986) found in her study of religiousness in terminally ill and healthy adults, that reported

well being was related less to the medical model of health and more to being able to get around. The importance of being able to be up, get out, move about, and be useful was repeatedly commented on by the most debilitated patients in the present study. The results of FIRM's mastery and health scale, and results of Reed's study support the view that mobility is used by patients as a judge of their well being more than the medical diagnosis.

Resource Meaning: The Concept of Work

One of the most important findings of this study is the notion that patients and spouses engage in several types of work in order to manage the major task they are facing, and that they utilize energy and resources in order to accomplish their work goals. The concept of work evolved as a result of the realization that patients and spouses were expending energy to manage their situation. Also, they used words and phrases such as, "it's hard", "it's difficult", "do as well as you can", which are usually associated with work, to describe their reactions. In addition, they identified resources which they used to help them manage. Energy expenditure, descriptive words, and resource use completed the requirements necessary to permit the view that patients and spouses were working.

The overall concept of work is presented first with

reference to how patient and spouse work relates to existing ideas of work in society. Work is also discussed as a way of providing a context for coping and coping behaviors. Secondly, other types of patient and spouse work identified in the literature are described with discussion on how this current investigation contributes to this body of knowledge. Finally, the fit between patient and spouse work, as previously described in chapter four, is discussed with regard to the object of their work, similarities and differences in their work and the perspective of time.

The Concept of Work

The idea of work is not foreign to North Americans. The phrase "protestant work ethic" describes a belief that being busy at a worthwhile endeavor for most of the day is to be valued. Work is usually thought about in relation to an occupation with financial or other types of return. However, in addition to being used to describe an occupation, work is also used to explain efforts required to build interpersonal relationships; children's play is often called work. Work is considered an appropriate way to describe what a person does to deal with grief. The notion that patients and spouses work on their own behalf to deal with advanced cancer is an expansion of the concept of work. Previously, work has been narrowly defined and

used to describe behaviors dealing with a limited part of the human experience. The results of this study support a broader view that includes a variety of types of work applied toward dealing with a diagnosis of advanced cancer in the family. Work, as it is described in this investigation, provides the context for behaviors used by patients and spouses as they deal with advanced cancer. There is perhaps less tendency to view people as passive recipients of professional care when their activities are viewed as work.

It seems to be helpful to view behaviors such as "keeping busy" and "not dwelling on it" as attempts to control oneself within a bad situation, survive a situation, or get on with daily living, than to have these behaviors as part of a list labelled as denial or distraction techniques. Although it is true that at times people use denial or distraction, this study points out that these techniques are helpful in confronting the disease and in order to continue to live as normal a life as possible. The concept of coping and coping strategies also benefit when viewed within a concept of work.

Coping, as a general concept, can be applied to both patient and spouse responses to advanced cancer. Lazarus and Folkman (1984) noted that the process of coping must be examined in a specific context. They state that to be able to study and evaluate coping, one must understand what the person is coping

with, and that the more narrowly defined the context is the easier it is to link a particular coping thought or action to the contextual demand (p. 142). Viewing actions and thoughts of patients and spouses dealing with advanced cancer in the home as contributing to the accomplishment of specific types of work provides that contextual view. Coping functions defined within specific contexts are less general and more situation specific (Lazarus and Folkman, p. 149).

Viewing patient and spouse behavior in the context of work to be done shows that although some of their behaviors are the same, what they hope to accomplish is different. Some of the early work which identified that patients go through stages as they face death (Kubler-Ross, 1972) has been taken to mean that each person moves in a set sequence through set stages, and that ideally each person should go through to a stage of acceptance. Clinical discussions have been overheard that include the family in these stages as well, even though Kubler-Ross identified stages from talking with dying patients not families. Nor was it her intent to have sequencing occur as a result of these stages. Utilizing the view that patients and families work and that they have different work to do helps to prevent this tendency to sequence patients through stages (Gullo, Cherico and Shadick, 1974). The concept of work also provides some additional information about the coping strategies suggested by Weisman

(1979). Weisman looked at newly diagnosed cancer patients and listed 15 strategies he observed in patients trying to manage this situation. Viewing these strategies from the point of view of resources used in order to accomplish certain work provides additional information about what is happening to patients and spouses in a cancer situation. For example, understanding that the distraction technique of "doing things" helps patients carry on with daily living and assists them to keep their spirits up, which in turn supports their families, allows a more complete view of not just a coping strategy, but what patients hope to accomplish by using a particular strategy.

Patient Work

The fact that patients have work to do was first noted by Janis (1958) who described certain behaviors he had observed in surgical patients as they anticipated surgery. He called this anticipation process "worry work" and stated that patients used mental activities to prepare themselves for the crisis of surgery (p. 375). Janis felt that this worry work enabled individuals to adjust better to a painful situation and if the work was not done individuals were at a disadvantage post surgery. Janis did not provide elaboration on what these mental activities were or how they helped patients to prepare. However, he did note that information from the physician was essential if patients were to

complete their worry work. A similar type of work was noted from the results of the current study. Preparing work in this study included behaviors patients engaged in to prepare their families, as well as themselves, for an inevitable or uncertain outcome. The mental and physical activities which were a part of preparing work differed for the two groups of patients. Patients who were members of the uncertain group, like Janis' (1958) patients, worried about preparing their families. On the other hand, patients who were members of the inevitable group gave specifics about how they were preparing their families and themselves. One patient, who was a member of the inevitable group, described his funeral plans; two other patients, who were also members of the inevitable group, outlined how they were to be looked after once they were not able to be up and about. The stage of illness had an impact on the degree patients had progressed from worry to action. For patients in the current investigation, like Janis' patients, information was essential in order to make specific plans. The importance of information for family and patient decision making has also been noted by others (Hine, 1980; Derdiarian, 1986; Degner and Beaton, 1987).

Portions of other patient work, identified in this present study, could be a part of what Janis (1958) identified as mental activities that the patients utilized prior to surgery. Patients in this study described the use of mental relaxation techniques

and other mental activities, such as purposefully not dwelling on the situation by thinking or doing something else in order to control themselves. Fighting work, which involved doing the best they could against the disease, may also have been a part of what Janis observed in patients presurgery. The notion of patients working was not picked up by other writers until recently.

Specific work patients engage in while hospitalized has been noted in three publications (Stepter, 1981; Strauss, Fagerhaugh, Suczek, and Wiener, 1981; Fagerhaugh, Strauss, Suczek and Wiener, 1987). Strauss et al. (1981) discuss a number types of work engaged in by hospitalized patients. Although the setting was different and the authors do not provide information on patient diagnosis, some of the work described by Strauss et al. is the same as patient work found in the current study. For example, Strauss et al. described patients' "body work" as expenditure of energy and time along with courage and will to maintain composure, control their bodies for tests, and look to their own comfort needs. In this present study, the efforts of daily living work for patients also involves using energy to attempt to live as normal a life as possible. Hospitalized patients would not have had the same demands for normal living as patients at home. Therefore, certain work and goals may be different for patients at home vis a vis patients in the hospital.

Fagerhaugh et al. (1987) describe patient safety work in a

technologicalized hospital. The authors identify such behaviors as monitoring IV's and selecting which staff they would prefer do certain procedures as examples of patient safety work in a hospital. They allude to the fact that families are also involved but do not give any details of family work which may be different than patients' work. Their findings are based on two years of field work and interviews in six hospitals with over 100 staff and patients. Details about diagnosis, stage of disease or treatment are not provided. Work focus, as noted in the current investigation, changes by disease stage and spouses engage in different types of work than do patients.

Spouse Work

Although very little has been written about patient work, even less has been published about the possibility that spouses engage in work when their husbands or wives are seriously ill. Fagerhaugh et al. (1987) mentioned that families have safety work to do when a loved one is hospitalized; they imply however that the work is the same for both patients and families. The results of this current study show that although some of patient and spouse work requires similar behaviors only one area of work is the same for both patients and spouses. An element of safety work as described by Fagerhaugh et al. was reported by spouses in the current study and categorized under helping work. One spouse

outlined her concern while her husband was hospitalized that the nursing staff were not caring for his Port-A-Cath the way in which she and her husband had been taught to care for it at home and she was worried that the staff would plug it. The same spouse described her efforts to have her husband moved when he was admitted to the same room as a smoker. Helping work activities, which involved concern for patients' safety at home, were such things as "watching that he doesn't get dizzy and fall" and "ensuring that she is not left alone".

Although references to the fact that families have work to do during a loved one's illness have not been included in published reports, the idea that families work post death has been reported in the grief literature. Lindemann (1944) in his class description of grief responses, used the term "grief work" to encompass all behaviors individuals display in order to become separated from the deceased and readjusted to life without their loved one. If it is appropriate to think of an individual as engaging in work after the death of a loved one, then it would also seem to be appropriate to think of an individual engaging in work prior to the loss as well. The goal, focus and object of the work would be different. For example, part of grief work for an individual is to separate from the deceased. Results of this current study show that spouses are mainly concerned with doing all they can for their husbands and wives and consciously try to

spend as much time as possible with them. This finding was also reported by Silverman (1974) in her study of 39 women whose husbands had suffered long term illness. Silverman's study involved doing follow up interviews with the widows three weeks after their husbands' death. Although there is lack of agreement in the literature concerning the labelling of some predeath reactions in survivors as anticipatory grief, some parallels exist between what writers have identified as anticipatory grief reactions and what has been identified as spouse work in the present study. These parallels will be discussed later in the chapter.

Fit Between Patient and Spouse Work

Findings from the present study, in which patient and spouse behaviors were identified as work they do in order to deal with advanced cancer in the home, are similar to behaviors described by others in related research. Mages and Mendelsohn (1979) describe a variety of tasks patient have to do depending on stage of disease. The concept of anticipatory grief, as outlined by Rando (1986) also contains elements of patient and family behaviors similar to those noted in the present study. This section presents discussion of the relation of these concepts to the findings of patient and spouse work as outlined in the present study. The object of patient and spouse work is

discussed first, followed by a review of work similarities and differences, and lastly the perspective of time as viewed by patients and spouses is discussed.

Object of Work

The image of patients and spouses working to manage a diagnosis of cancer has not been directly discussed in any published information. Research on patients in different disease stages by Mages and Mendelsohn (1979) however, has provided information on patient behaviors and tasks which agree with the findings of the current study. Mages and Mendelsohn carried out semi-structured interviews with two retrospective samples; one sample (N21) was 6 to 12 months post treatment and the second (N35) was 3 to 6 years post treatment. They also interviewed a third group of patients (N31) who were receiving or had just received treatment. From their study, Mages and Mendelsohn identified seven issues that patients must deal with depending on disease stage. These issues include managing the discovery of cancer and its primary treatment, dealing with recurrent disease, and managing terminal illness. Each issue required an adaptive task. For example, the adaptive task for terminal illness was to prepare to leave family and friends, provide for loved ones, learn to use medical assistance and internal resources to minimize pain, and so on (p. 265). Although, Mages and

Mendelsohn call this one task, it would seem to be a number of tasks of which many agree with the findings of the present study. The work of preparing families, as identified in the present study, parallels well with the adaptive task related to terminal illness. However, patients in this current study engaged in much more work than preparing to leave their families or providing for their families. They also used energy and resources to maintain the support of others, carry on with daily living, fight the disease and so on. In fact, patients in the current study had work to do which was similar to tasks identified by Mages and Mendelsohn as occurring in patients who were experiencing the possibility of recurrence. The tasks identified by Mages and Mendelsohn were listed as being specific to a particular disease stage without overlap. In the present study, patients in both groups had the same work but the focus of the work was more specific for patients in the inevitable group. The stage of disease did have an influence on patient work but not to the point of the work being different as noted by Mages and Mendelsohn.

The main object of spouse work in the current study was the patient. Spouses were more concerned about patients than they were about themselves as was evident by the fact that out of five categories of work only one was directed toward spouses themselves. Others have also noted that spouses are more

concerned about patients than themselves (Wright and Dyck, 1984; Howell, 1986). However, spouses in the current study were also aware that patients' well being depended on them remaining healthy and in good spirits; therefore, a large amount of their energy and resources were used to survive. The results of Howell's (1986) descriptive study of 30 spouses of cancer patients also showed that spouses had to manage unpleasant thoughts, find someone to share their feelings with, and deal with the effect the disease was having on the children. Spouses in Howell's study also had as their object of concern others, including patients and children, and lastly themselves, without discussion of possible efforts on their part towards the disease. As in the current study, patients were the only ones who could directly work on the disease.

Work Similarities and Differences

Only one type of work, hoping work, was the same for both patients and spouses. The extent that patient and spouse work differs may contribute to the isolation and communication difficulties in families often reported in the literature (Giacquinta, 1977; Krant and Johnston, 1978; Reilly and Patten, 1981). If there are times when patients, in order to fight the disease, use their anger as an energy source, spouses may experience discomfort in their relationship. There will also be

times when the work of one group compliments the work of the other. This can be seen in the area of daily living work for patients and helping work for spouses. Patients wish to go on with life as normal and do normal things and spouses work to maintain a role for the patients and give them something to do. Others have also noted the importance of maintaining normal life activities for patients (Chalmers, 1984; Thorne, 1985). In her study of eight families, Thorne reported the importance of living normally in spite of the disruptions caused by cancer. To her subjects, normal meant being able to "go fishing" and "do things". Chalmers discusses similar findings in patients with chronic airflow obstruction. She noted that patients attempt to place their illness into a framework of normality.

Another area of difference for patients and spouses was in the degree of uncertainty displayed by individuals, especially among patients and spouses in the inevitable group. Patients in the inevitable group were able to acknowledge the fact of their impending death. Spouses, on the other hand, had difficulty with the fact that their husbands and wives were going to die. They reacted by "not thinking about it" and determining to "cross that bridge later". Perhaps only patients can view their own death as inevitable, leaving spouses to perceive patients' death as uncertain regardless of whether patients themselves view it as inevitable or uncertain. Spouses, at the time of the interviews,

may not have been able to acknowledge that the patient's death was inevitable. Doing so would have communicated a sense of giving up and in the spouses' view it was important for the well being of the patient to be positive. Silvermann (1974) noted a similar reaction in the wives of terminally ill husbands in her study on anticipatory grief. In the present study, the strain of this ambiguity showed in the interviews. Generally, the spouses' reactions were more emotionally intense, that is, they displayed more sadness than patients did during the interviews. Four of the seven spouses cried at some time during the interviews: only one of the seven patients cried.

The concept of anticipatory grief, as presented by Rando (1976) shows similarities to some of the types of patient and spouse work found in the present study. In her work, Rando identified certain tasks of a dying patient as examples of anticipatory grief. For example, these tasks included arranging wills, coping with loss, planning the future through allocation of time and energy, dealing with numerous psychosocial problems, and so on. Many of these tasks parallel the findings of the present study and are merely given different terms and placed within the context of work rather than grief. Anticipatory grief, as a way of looking at patient reactions, does not allow as broad a view of other patient tasks which involve such things as hoping, maintaining support, getting on with daily living, and

fighting the disease.

Better agreement exists between anticipatory grief and some spousal work. This is especially notable in the work of taking stock and preserving. In these areas of work, spouses review the patients' character and their life together and create or review memories. Rando (1986) describes these same features as examples of a family's anticipatory grief reaction through striving to take in the loved one and putting images into the mind so that these pictures will remain after the patient's death. Better agreement seems to exist between the findings of this study and what has been labelled by others as anticipatory grief. However, the results of the present study show that although the dying patient is the most important individual to spouses, they also are very much involved with their own survival and that of their children.

Time Perspective

Spouses were not as involved with the future as were patients. Rando (1986) also reported many of the patient tasks were future oriented. However, she noted that families were also involved in making plans for the future which did not involve the dying person. The results of the present study do not support that spouses are involved in removing their husbands and wives from their future plans. In fact, spouses were not looking at

the future at this point. They were more concerned with enjoying each day and making the best of the time they had left as a couple. It may be that because patients in this study were up and about and involved with the family, in spite of their pain and debility, spouses were not forced to look at the future without their husbands and wives. Rando (1986) does not indicate degree of debility of the patients in her work and it may be that as patients become increasingly bedridden, spouses are forced to view the future as it will be without their loved one.

Implications for Practice and Research

The purpose of this study was to identify what resources patients and spouses used to manage care of someone with advanced cancer in the home. The concept of work that evolved from the conceptual analysis requires additional investigation with more individuals in different life stages and settings to ensure its validity before it can be assumed as a guide for nursing practice with patients and families experiencing advanced cancer. However, even prior to further validation of the concept, the idea that patients and spouses are actively working on their own behalf does have implications for the practice of nursing in caring for these individuals.

Implications for Nursing Practice

The notion of patients and spouses as workers removes any sense that they are passive recipients of professional care. This fact alone may change previous reluctance on the part of health care professionals to share information with patients and families. The difficulty patients and families have in acquiring information is repeatedly noted in studies (Wright and Dyck, 1984; Degner and Beaton, 1987). Patients and spouses, in this study, wanted information on the disease, its prognosis, and treatment, and they wanted this information given in understandable terms with a compassionate manner. An information role for nurses was identified by patients and spouses to allow them to deal with physical care needs for specialized infusion devices and equipment.

Methods of providing emotional support to patients and families have always been a challenge for nurses in oncology. Nurses are consistently referred to as providers of emotional support; however, what that means is rarely addressed. The notion that patients and spouses work and that at times their work may be different, leading to conflicts within relationships, can assist nurses in their support role by allowing them to interpret reasons for possible conflicts to patients and spouses thus helping them to understand interpersonal dynamics which may be occurring within the family. In addition, the knowledge that spouses need to review their lives with patients and to discuss

their husbands and wives' character, can assist nurses to identify a method of providing further emotional support through listening to these life reviews. It was also clear from this study that patients need to discuss the seriousness of the disease with outsiders and that nurses can fulfill this role as well.

The realization that spouses have helping work, which involves maintaining a role for the patient and protecting the patient, can help nurses understand protective behaviors which are often noted when patients are hospitalized and may assist in preventing misunderstanding on the part of hospital staff and families.

Community nurses may be able to communicate the needs of families, in which a member has a serious illness, for their friends to provide short frequent visits rather than long infrequent ones. Spouses may need assistance to realize that they require diversion from the illness, especially as the disease progresses. The realization that spouses play a very important role in supporting the patient and carry most of the concern for patients and any children, make them a vulnerable group which nurses must observe for signs of fatigue. Spouses' devotion to their husbands and wives may not allow them to take time for their own health and nurses may need to reinforce that spouses care for themselves, as well as the patient, without

feeling guilty about needing to be away from the situation occasionally.

Nurses must recognize the painful experience of telling children, as was noted in the study, and assist families to transmit information in a hopeful manner.

Further Research Needs

From the results of this study, work has been identified as an important concept by which to understand the behaviors and mental reactions of patients with advanced cancer and their spouse/caregivers. Further investigation with larger numbers of individuals in different settings and at different stages of disease and the life cycle is required in order to validate and further develop the concept of work. Questions which remain to be answered are:

1) Do different categories of work occur in families which are at different points in the life cycle?
2) What work do other family members become involved in?
3) What specific types of work are children involved in?
4) How does work differ for hospitalized patients and families?
5) How does professional health care work and patient spouse work differ?
6) How are work categories influenced by type and stage of disease?

No attempts were made to delve into the unconscious through drawings or dream reports; it may be important to identify possible unconscious work of patients and spouses.

Certain resources identified in this study as important require additional investigation. The role of religion, spirituality, and faith was not investigated in depth, but appeared to play an important role for some patients and spouses. What is meant by faith, religion, and spirituality and how these resources can or cannot be supported by health care professionals requires further study by qualitative methods in order to identify the components of spirituality and faith and their differences or similarities to religion.

It was noted by couples who had children still at home that this was a very difficult time for everyone. What effect a parent's diagnosis of cancer has on children needs exploration, not just from the point of view of work but also with a view to identify the concerns, problems, and impact of the disease, as well as what children do to manage the situation.

Results of this study showed that some difficulties were encountered by spouses of patients in the inevitable group when they attempted to get information from their husbands and wives. These same difficulties were not reported by spouses whose husbands and wives were in the uncertain group. A longitudinal study would be needed to investigate where and to what degree

information sharing changed as the disease progressed. An article published in 1966 is still being quoted as a source for the fact that patient communication is minimal in areas dealing with death and dying (Abrams, 1966). A more recent publication reported that patients and caregivers (family and friends) did not speak openly about terminal illness (Reilly and Patten, 1981). In contrast, all couples in this study spoke openly about the disease and its prognosis during the interview involving both of them. Some patients in the uncertain group, in speaking about the emotional aspects of the disease, indicated that talking to their spouses constantly about their feelings would not be helpful, but that they did talk about the disease and its treatment. A specific study dealing with the patterns of communication such as what types of communication help, what hinders, and who talks to who about what requires further investigation. The agony of patients who feel they have been deceived or have had information withheld is something families carry with them into every ensuing relationship with health care personnel. Just what it is that prevents patients and spouses from obtaining the information they need clearly requires further study.

Limitations and Strengths

This was a descriptive study meant to investigate what

resources patients and spouses used to manage advanced cancer at home. The intent of the study was to identify concepts and themes of resource use in the home by the patient with advanced cancer and the spouse caregiver. The descriptive in-depth nature of the study and the financial and time restraints of the researcher prevented a study with large numbers of individuals. Therefore, the small sample size precludes any generalizable results. However, as indicated, the intent of the study was not to provide quantitative information which could be applied to similar populations, but to identify information which could be used to further develop theory dealing with patients and spouse/caregivers resource use in the home. Further studies are required in order to investigate the concept of work with other subjects in different age groups and dealing with other diseases.

The study could have been strengthened if the same subjects were followed through the disease stages to discover such things as changing communication pattern and information sharing behaviors. Different work categories may also have evolved as patients and spouses encountered different disease stages. Time was limited however and a longitudinal study was not possible.

It was decided not to include patients who had unresolved physical or emotional problems and this decision may have eliminated a population which could have contributed important information. In addition, 13 couples were approached in order to

recruit 7 couples. Therefore, it would be important to know the differences between couples who agreed and those who did not. Reasons volunteered for not participating were as follows: one male patient did not wish to discuss his cancer; another male patient felt it would be of no help to him; three female patients agreed but their spouses refused; and one couple agreed but a mutually acceptable time could not be agreed upon. It is interesting to note that most of the refusals were male initiated and even in the seven couples who participated, one male spouse was only participating "because my wife wants to do this". The apparent difficulty in getting men to participate in this type of research warrants further thought on the part of researchers. Perhaps the interview methodology is not comfortable for men or it may be that they are not comfortable with female interviewers. Whatever the case, one must question how representative the men who participated in this study are of the larger male population who are spouses of cancer patients or cancer patients themselves.

The question of helpfulness of each resource was not explored in depth as initially intended. As the interviews progressed and subjects were given the freedom to expand on their answers, many times the question of helpfulness of a particular resource was not appropriate or sensitive of the milieu of the interaction.

A strength of the study was that it looked at both patients

and spouses at the same time for the same reason. The resulting information allowed a comparison of what was happening for each member of the couple. A serendipitous strength resulted when patients were obtained at slightly different stages of their disease, resulting in the identification of two groups of patients and the findings of different tasks and work focuses for the two groups.

Although study limitations must be taken into consideration, the findings of this study resulted in identification of important resources for patients and spouses and showed how active these couples are in dealing with the disease. These are important issues for nurses to understand who work with patients with advanced cancer and their families. The study also identified further questions for research and revealed that information obtaining and sharing continues to be a problem. Conceptual analysis of the interview data revealed that patients and spouses "work" to manage advanced cancer in the home. Patients and spouses described several types of work, each with a different goal and focus. The concept of work adds to the understanding of other concepts; such as coping. Work provides the context in which coping occurs. Viewing patients and spouses as workers helps to prevent viewing individuals with cancer and their families as passive recipients of the work of health care professionals.

The fact that there are different types of work for patients and spouses is information that is useful for practitioners as they support families during this very difficult time. The understanding that at times patients and spouses may be engaged in work which conflicts will be helpful for practitioners as they attempt to assist patients and spouses to understand the events which are unfolding in their lives.

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APPENDIX A

FIRM

FAMILY INVENTORY OF RESOURCES FOR MANAGEMENT

APPENDIX A

FIRM

FAMILY INVENTORY OF RESOURCES FOR MANAGEMENT

Pages 145 to 147 inclusive have been removed due to copyright restrictions. These pages contained the resource measurement instrument FIRM - Family Inventory of Resources for Management by Hamilton I. McCubbin, Joan K. Comeau, and Jo A. Harkins. Information concerning FIRM may be obtained from the

Family Stress, Coping and Health Project
School of Family Resources and Consumer Sciences
University of Wisconsin Madison
1300 Linden Drive
Madison, Wisconsin 53706
Phone: 608-262-5712

APPENDIX B

FOCUSED INTERVIEW SCHEDULE

APPENDIX B

FOCUSED INTERVIEW SCHEDULE

INTRODUCTION

I am interested in learning what resources are being used by people with cancer and their spouses in the home situation. By resource, I mean both the tangible and the intangible things which you have used or are using to manage care at home. An example of tangible items might be things like medical devices, such as canes, dressings and so on, or having someone give you help with your care or housework, An example of intangible resources might be talking to someone about your feelings, or thinking positive thoughts.

PART I

Initial Questions to Aid in Establishing Rapport and to Obtain General Information Regarding the Participant's Interpretation of the Term "Resources"

To be completed with each individual.

1. What has it been like for you managing the care of _____ at home?

   What has it been like for you being cared for at home?

2. What does the word "resource" mean to you?

3. What kinds of resources are you using to manage this situation?

   a) How did you learn of the resource?

   b) Where have you obtained these resources (what has been the source of the resources noted above)?

   c) How helpful/not helpful have the resources been?

PART II

Specific questions will be used if probing is required due to an unclear understanding of resources or a failure on the part of the participants to recall what exact resources are being used.

A. Physical Resources

1. What kind of medical equipment are you using?

   a) How did you obtain it/hear about it?

   b) How helpful/not helpful has this equipment been?

2. What physical help have you had to give care at home/what physical help have you had in order to stay at home?

   a) Who provides this help?

   b) How helpful or not helpful has it been?

3. What community resources have you used (examples if required are such things as meals on wheels, support groups, yard work help, homemakers, transportation help)?

   a) How did you hear about these resources?

   b) How helpful/not helpful have they been?

4. What financial resources have you used?

   a) What was the source of the help?

   b) How helpful/not helpful has it been?

5. What health care resources have you used in the home (examples are physiotherapy, nurses, orderlies)?

   a) How did you hear about these resources?

   b) How helpful/not helpful have they been?

B. Emotional Resources

1. What resources do you use for recreation (example if required: fun time such as games, T.V. watching, reading, social evenings, or going out)?

   a) If appropriate, the source will be explored with the participants?

   b) How helpful/not helpful have these things been?

2. What resources do you use to manage your feelings about this situation of caring for your spouse/of being cared for by your spouse (example, talk to someone, read, get out and keep busy)?

   a) What or who has been the source of this help?

   b) How helpful/not helpful have these things been?

3. What people/person do you want to be with during this time (who is closest to you)?

   a) What do they provide for you?

   b) How helpful/not helpful has this help been?

4. What helps you when you feel afraid, worried, angry, guilty, sad?

   a) What is the source of that help?

   b) How helpful/not helpful has it been?

5. What helps you feel hopeful, happy, peaceful?

C. Spiritual Resources

1. What inner resources are you using to manage this situation?

2. What mental activities have you used (example: meditation, prayer, yoga)?

3. What formal religious resources do you use (for example, attend church/synagogue or see your clergy)?

D. Informational Resources

1. What have you read or been told which you have used to manage care at home/to manage being cared for at home (probing questions which will be used to seek out exact type of information, will include such things as disease related information, prognosis information, what can be expected, care approaches, use of equipment or drug information)?

   a) What has been the source of that information?

   b) How helpful has this information been?

   c) Have you received any information which you consider to be not helpful?

2. What information have you used to help you make your decisions in this situation (probing if necessary to investigate coordinating efforts like legal issues, treatments and arranging care)?

   a) What has been the source of this information?

   b) How helpful/not helpful has this information been?

PART III

Final general questions to be asked at the end of the final interview with each individual and each couple at the closing interview.

1. Situations like this one have some effect on all who are involved - though some experience greater effects than others. How has this situation affected you as a couple, your family?

2. What recommendations would you have for other couples in this situation?

3. What recommendations would you have for nurses and others who may be responsible for making resources available to you?

4. What effect, if any, do you feel taking part in these interviews has had on you?

APPENDIX C

GUIDE FOR REVIEW OF INTERVIEW SCHEDULE

APPENDIX C

GUIDE FOR REVIEW OF FOCUSED INTERVIEW SCHEDULE

As you review the Interview Schedule, please apply the questions outlined below to each interview question. Each time you answer "no", please provide me with your reasons for answering that way. You may make your comments directly on the Interview Schedule.

1. Is the question appropriate given the research?

2. Is the wording clear and understandable?

3. Have the questions included sufficient kinds of resources to cover the scope of resources you have encountered/used in the community?

4. What additional questions would you suggest be included?

Thank you for your assistance in this research. I hope it will lead to better understanding of how patients and families manage care at home.

APPENDIX D

LETTER OF EXPLANATION

APPENDIX D

LETTER OF EXPLANATION

Dear _____:

I am a graduate student in the Masters of Nursing program at the University of Alberta and I am also the Education Coordinator, Department of Nursing, Cross Cancer Institute on Educational Leave. I am presently doing a study on the resources which people use to care for someone with cancer at home. It is often much better for people to be cared for at home rather than in a hospital setting, but providing care at home can be demanding for both the people with cancer as well as for their spouses. I feel we, as health care providers, could be much more helpful to people in similar situations, if we knew more about what people do on their own behalf to manage care at home. For that reason, I would like to set up an appointment with you and your spouse to discuss my study with you and to invite you both to participate in the study. If you agree, I will be asking for three additional meetings. The first meeting would be with both you and your spouse to explain the study and obtain your consent. I would then ask for 2 one-hour interviews separately with each of you. If you have any questions, please call me at 439-5445.

I hope that this study will provide important information for further understanding of home care for people with cancer and I look forward to discussing this project with you.

Sincerely,

Nola Williams, R.N., B.Sc.N.
Graduate Student
Masters Program
Faculty of Nursing
University of Alberta

Education Coordinator
(On Leave)
Cross Cancer Institute

APPENDIX E

CONSENT TO STUDY FORM

APPENDIX E

CONSENT TO STUDY FORM

RESOURCE USE IN THE HOME BY THE PATIENT WITH ADVANCED CANCER AND THE SPOUSE CAREGIVER

Principal Investigator: Nola Williams, R.N., B.Sc.N.
Graduate Student, Masters Program
Faculty of Nursing,
University of Alberta
439-5445

Faculty Advisor: Dr. E. Davies
Associate Professor
Faculty of Nursing
University of Alberta
432-6253

The intent of this study is to discover what resources the spouse/caregiver and the patient use to manage the cancer situation in the home. Through two one-hour interviews held separately with each of you, I hope to be able to seek out patterns of resource use, sources of help and helpfulness of the resources used. Also, you will each be asked to complete a pencil and paper check list inventory of family (meaning the two of you) resources developed for use with families who are caring for a chronically ill member. You will be given an opportunity to look at the interview questions and the inventory prior to agreeing to participate.

I, _____, have had the above study explained to me and I understand that the purpose of the study is to identify the resources patients and spouses use to manage care at home. I understand that:

- there may be no benefit to me personally;
- some of the questions may be of a disturbing nature;
- I may withdraw at any time without negative effect on my care;
- I may refuse to comment or answer any question at any time without withdrawing totally from the study;

- I will be able to stop the interview at any time;
- it is not the researcher's intent to provide health care; however, in the event of a serious concern, referrals will be made to a nurse in the Cross Pain and Symptom Control Clinic/

I expect that:

- I will be interviewed in my home two times for one hour each time over a period of 10-14 days;
- the researcher will be observing me during the interviews;
- the interviews will be taped and transcribed, but any identifying information will be removed and only the researcher will be aware of my identity;
- the tapes will be listened to and analyzed by the researcher and her faculty advisor;
- upon completion of the study, the tapes will be erased;
- confidentiality will be maintained throughout;
- publications resulting from this investigation will not contain any identifying information or names.

I have been given the opportunity to ask questions and realize that I can ask for additional information at any time. I will be given an opportunity to see a summary of the final report.

I understand what is required of me and I freely consent to be a part of this study.

_____ _____

PATIENT WITNESS

_____ _____

SPOUSE DATE

I agree to participate in this study.

_____ _____

ATTENDING PHYSICIAN DATE

APPENDIX F

DEMOGRAPHIC DATA FORM

APPENDIX F

DEMOGRAPHIC DATA FOR THE MARITAL DYAD

Date _____ Dyad Code _____

Patient Code _____

Spouse Code _____

Patient DOB _____ Diagnosis _____

Spouse DOB _____ Stage _____

Patient's Gender M F Date of Diagnosis _____

Length of Time of Spouse in Caretaking Role _____

Number and Age of Children (M)_____ (F)_____

Number of People in the Household _____

Length of Marriage _____

Education: Number of years of school completed

Patient:	Grade School	1	2	3	4	5	6		
	Junior High	1	2	3					
	High School	1	2	3	4				
	College	1	2	3	4				
	University	1	2	3	4	5	6	7	8
Spouse:	Grade School	1	2	3	4	5	6		
	Junior High	1	2	3					
	High School	1	2	3	4				
	College	1	2	3	4				
	University	1	2	3	4	5	6	7	8

Ethnic Background:

Patient _____

Spouse _____

Religion:

Patient:	Protestant	Catholic	Jewish	Muslim	Other
Spouse:	Protestant	Catholic	Jewish	Muslim	Other

APPENDIX G

FILE CARD INFORMATION

APPENDIX G

FILE CARD INFORMATION

Name:

Dyad Code _____

Patient _____

Patient Code _____

Spouse _____

Spouse Code _____

Address _____

_____

Phone Number _____

Number and Length of Visits:

_____

_____

_____